



PHD

Factors influencing treatment decisions for patients with colorectal cancer

Sanders, Tom

Award date:
2000

Awarding institution:
University of Bath

[Link to publication](#)

Alternative formats

If you require this document in an alternative format, please contact:
openaccess@bath.ac.uk

Copyright of this thesis rests with the author. Access is subject to the above licence, if given. If no licence is specified above, original content in this thesis is licensed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International (CC BY-NC-ND 4.0) Licence (<https://creativecommons.org/licenses/by-nc-nd/4.0/>). Any third-party copyright material present remains the property of its respective owner(s) and is licensed under its existing terms.

Take down policy

If you consider content within Bath's Research Portal to be in breach of UK law, please contact: openaccess@bath.ac.uk with the details. Your claim will be investigated and, where appropriate, the item will be removed from public view as soon as possible.

FACTORS INFLUENCING TREATMENT DECISIONS FOR PATIENTS WITH COLORECTAL CANCER

**submitted by Tom Sanders
for the degree of PhD
of the University of Bath
2000**

Copyright

Attention is drawn to the fact that copyright of this thesis rests with its author. This copy of the thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with its author and that no quotation from the thesis and no information derived from it may be published without the prior written consent of the author.

This thesis may be available for consultation within the University Library and may be photocopied or lent to other libraries for the purposes of consultation.

A handwritten signature in black ink, appearing to read 'T. Sanders', is positioned below the library consultation notice.

UMI Number: U141898

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



UMI U141898

Published by ProQuest LLC 2013. Copyright in the Dissertation held by the Author.
Microform Edition © ProQuest LLC.

All rights reserved. This work is protected against
unauthorized copying under Title 17, United States Code.



ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

UNIVERSITY OF BATH LIBRARY		
3	14 NOV 2000	
phd.		

ACKNOWLEDGEMENTS

I would like to thank the Medical Research Council (MRC) for funding this study. Thank you to Margaret Robbins and Suzy Skevington for their invaluable guidance and support in supervising the project over the four years. I am extremely grateful for the support and cooperation that I received from the staff and patients at the Bristol Oncology Centre. Finally, I would like to thank my wife Caroline for all her support and encouragement over the years, and to Sebby who kept me awake at night, presumably to help me finish the thesis as quickly as possible.

Abstract

The study aimed to investigate the treatment decision-making process and information needs of colorectal cancer patients, with reference to recent policy developments in cancer care.

Semi-structured interviews were conducted on two separate occasions with recently diagnosed colorectal cancer patients. The interviews were carried out using a tape recorder and were subsequently transcribed in full. Structured observations of oncologist-patient consultations were conducted to examine the nature of interactions and the treatment decision-making *process*. The interview transcripts and observation notes were analysed using a 'coding-frame' where categories were grouped according to the relevant themes. The data were analysed with reference to the original interview transcripts and observation notes in search of emergent categories. The participants were recruited for interview from a large oncology department in the South West region. All interviews were conducted in the informants' own homes. Observations of 87 interactions between oncologists and colorectal cancer patients were carried out during a weekly outpatient clinic. 37 patients were interviewed initially, and 28 were re-interviewed five months later. A further 11 face-to-face interviews were carried out with oncologists and nursing staff at the department, and staff at Avon Health Authority.

This study provides new evidence of how treatment decisions are made in the cancer consultation, rather than simply how patients believe that they are carried out. Most patients required the doctor's treatment recommendation, and frequently engaged in a 'negotiation' with the oncologist in order to *avoid* having to make the decision alone. Thus, the study shows how the definition of 'patient participation' should be extended beyond dichotomous conceptions of 'participant' and 'non-participant'. Patients often felt that they had no choice but to accept the treatment option. The findings also show that patients experienced difficulty in understanding probabilistic information, which they frequently attempted to resolve by interpreting it in terms of a positive outcome. The study concludes that often patients were unable to make a treatment decision without the oncologist's advice, which suggests that oncologists should provide detailed explanations to patients and elicit their preferences, followed with a treatment recommendation. Patients were often expected to make immediate decisions, however, in view of the uncertainty surrounding cancer and its treatment, patients should be given more time in which to make their choice. This study also provides unique evidence of how patients decide to accept or reject the option of *treatment*, rather than how they choose between several different treatment *alternatives*.

CONTENTS

<i>Chapter 1 Introduction and Background.....</i>	<i>11</i>
Treatment decision-making in cancer.....	11
Investigating the communication process.....	12
Why study cancer?	13
Why choose colorectal cancer?	15
Using qualitative methods	16
The implications of treating Bristol as a case study	17
Conclusion.....	19
 <i>Chapter 2 Do Patients Want Participation or Information? An Exploration of the Evidence with Special Reference to Treatment Decision-Making in Cancer Care.....</i>	 <i>20</i>
Introduction	20
Treatment options.....	21
Variations in the management of colorectal cancer.....	22
Public perceptions of screening for colorectal cancer	25
Psychological responses to treatment and screening	27
Summary	29
Models of the doctor-patient relationship.....	30
Patient participation in the doctor-patient encounter.....	31
Barriers to patient participation in the doctor-patient interaction.....	32
Summary	34
The attitudes of physicians and cultural variations regarding truth disclosure.....	35
Summary	37
Patients' information needs.....	37
Summary	39
The influence of family presence in the consultation.....	40
Defining 'decision-making'.....	41
The importance of decision-analysis	43
The extent of patient participation in treatment decision-making	45
The evidence supporting patient participation in decision-making	46
Summary	48
The evidence against patient participation in decision-making	49
Summary	52
Factors influencing decision-making.....	53
Psychological factors.....	54
Summary	56
Survival	57

Summary	58
The effects of age	59
Social/cultural factors in decision-making	60
Summary	61
Physician related factors in decision-making	62
Summary	63
'Framing' effects	64
Summary	66
What is missing in the literature?	66
Types of studies conducted on decision-making	68
Conclusion.....	69
Chapter 3 Methodology.....	71
Introduction	71
Study aims and objectives	72
Access.....	73
Social access.....	74
Access to patients	74
'Informed consent' or 'process consent'?.....	75
The research setting.....	76
The sample	77
Data collection.....	78
Reasons for employing 'participant observation' methods	79
Conducting clinic observations	81
Learning the language of oncology	82
Emotional attachment.....	83
Semi-structured interviews.....	83
Conducting interviews in the field: the initial steps	85
Deciding on the interview style	85
Asking sensitive questions	86
Power in the interview.....	87
'Verification' and the interview process.....	88
Exiting the field.....	90
Conclusion.....	90
Chapter 4 Approach to Analysis.....	92
Introduction	92
'Interpretation' and 'analysis'	93
Analysing data whilst in the field.....	94
Organising data systematically.....	95
Formulating themes.....	97

Interviews	97
Coding method	99
Coding the data.....	99
Identifying concepts and trends in the data	100
Identifying associations	101
Using matrices to analyse data	103
'Sequencing' the data	104
Analysing interview and observation data together.....	106
Assessing data credibility	108
Representativeness of the data.....	109
Searching for 'negative cases'	110
Weighting the evidence	111
Adopting a systematic approach to analysis.....	112
Using grounded theory in the current study	113
Conclusion.....	116
<i>Chapter 5 Characteristics of the Study Population</i>	<i>117</i>
Introduction	117
Sampling stages	117
Living status of interview participants	138
Attrition rate of interview participants	139
The interviewees.....	141
Individual characteristics.....	143
The interviews (oncologists)	144
The interviews (nurses)	145
Conclusion.....	146
<i>Chapter 6 Social policy context of cancer care delivery.....</i>	<i>147</i>
Introduction	147
Pressures of patient throughput	148
Effects of cost pressures	150
The emphasis on primary care.....	152
Referral practices of surgeons	155
Contracting practices	156
Cost effectiveness.....	158
Establishing equitable service delivery	160
Rationing through the use of clinical protocols	162
Conclusion.....	165
<i>Chapter 7 Results and Interpretation</i>	<i>167</i>
Presentation of the Data.....	168
Identity of doctors	169

Risk perceptions	169
Modes of adaptation to uncertainty	185
Perceptions of choice in decision-making	189
‘Right’ and ‘wrong’ decisions	194
Shared or individual decision-making?	198
The role of family and friends in decision-making.....	202
‘Honesty’ and the negotiation of information.....	205
‘Reassurance’	212
Continuity of information.....	216
Social class and employment status.....	221
Family composition.....	222
Age and decision-making	228
Responses to side effects	236
Trust and decision-making	242
Maintenance of trust.....	245
Managing fear and maintaining hope	250
II. The role of oncologists in treatment decision- making	262
Introduction	262
The oncologist’s role in interpreting information.....	262
Levels of patient involvement within the interaction	263
Providing a treatment recommendation.....	267
Providing no treatment recommendation.....	273
Conclusion.....	279
Chapter 8 Discussion and Conclusion	284
Introduction	284
Patients’ perceptions of decision-making.....	285
The issue of treatment ‘choice’	287
‘Rational’ decision-making or ‘interpretative’ decision-making?	289
Role preferences in decision-making.....	290
Information needs.....	293
Continuity of information.....	295
‘Social Status’	295
Age	297
Gender	298
The need to encourage patient involvement in decision-making.....	301
The need to simplify complex information for patients.....	302
Having a choice is ‘no choice’	303
Patients do not want to make decisions alone	303
Communicating the ‘truth’	305

Some policy implications of the findings	305
Cost shifting	307
Contracting	308
Establishing greater equity or tighter control over priorities?	310
Conclusion.....	311
<i>appendices.....</i>	<i>313</i>
Appendix 1	313
Appendix 2	315
Appendix 3	320
Appendix 4	322
Appendix 5	325
Matrix	325
Bibliography.....	328

Tables

<i>Table 1: New registrations of colorectal cancer in England and Wales (1992) per 100,000 of the population</i>	<i>119</i>
<i>Table 2: New registrations of females with colon cancer in the South West Region per 100,000 of the population</i>	<i>120</i>
<i>Table 3: New registrations of males with colon cancer in the South West Region per 100,000 of the population</i>	<i>121</i>
<i>Table 4: New registrations of females with rectal cancer in the South West Region per 100,000 of the population</i>	<i>122</i>
<i>Table 5: New registrations of males with rectal cancer in the South West Region per 100,000 of the population</i>	<i>123</i>
<i>Table 6: New registrations of females with colon cancer in Avon Health Authority per 100,000 of the population</i>	<i>125</i>
<i>Table 7: New registrations of males with colon cancer in Avon Health Authority per 100,000 of the population</i>	<i>126</i>
<i>Table 8: New registrations of females with rectal cancer in Avon Health Authority per 100,000 of the population</i>	<i>127</i>
<i>Table 9: New registrations of males with rectal cancer in Avon Health Authority per 100,000 of the population</i>	<i>128</i>
<i>Table 10: Total number of new presentations to Bristol Oncology Centre between 1/1/96 and 31/12/96</i>	<i>130</i>
<i>Table 11: Total number of new presentations of colon and rectal cancer to Bristol Oncology Centre during recruitment period 1/1/96 to 23/9/96</i>	<i>132</i>
<i>Table 12: Numbers of new cases attending weekly clinic and numbers actually observed between 1/1/96 and 23/9/96</i>	<i>134</i>
<i>Table 13: Characteristics of patients approached for interview.....</i>	<i>136</i>
<i>Table 14: Living status of interview respondents.....</i>	<i>138</i>
<i>Table 15: Attrition rate of interviewees due to poor health and death</i>	<i>139</i>
<i>Table 16: Overall attrition rate</i>	<i>140</i>

Figures

Figure 1: <i>The effect of treatment 'benefit' on decision reached</i>	102
Figure 2: <i>Nature of decision-making under conditions of uncertainty</i>	105
Figure 3: <i>Regional and local incidence of colorectal cancer, and total number of cases attending Bristol Oncology Centre</i>	135
Figure 4: <i>Model of rational decision-making</i>	290
Figure 5: <i>Model of 'interpretative' decision-making</i>	290
Figure 6: <i>The 'negotiation' approach to decision-making</i>	290
Figure 7: <i>Decision-making without a treatment recommendation</i>	301
Figure 8: <i>Decision-making with a treatment recommendation</i>	301
Figure 9: <i>A model illustrating the degree of patient involvement in decision-making</i>	304

CHAPTER 1

INTRODUCTION AND BACKGROUND

Treatment decision-making in cancer

The nature and process of treatment decision-making, especially in cancer, has been researched extensively over the last two decades. In particular, the question of whether cancer sufferers want greater involvement in the decision-making process has received a lot of research attention. Also, a large body of evidence about the psychological impact of various treatment options on cancer patients' coping styles and their ability to adjust to illness has emerged in recent years (Cassileth et al, 1985; Ganz et al, 1985; Fallowfield et al, 1986; Fallowfield et al, 1990; Irvine et al, 1991; Hughes, 1993). However, much of this research has primarily focused on the decision-making process from the point of view of the patient, and largely in isolation of the clinician as well as the wider organisational context. This study attempts to rectify some of the gaps inherent in previous research, by using a combination of in-depth interviews and observation methods to explore the *process* of treatment decision-making in the case of colorectal cancer.

A central question that this study attempts to answer is how far colorectal cancer patients actually participate in the treatment decision-making task, rather than simply how much they would like to participate. In view of the changing public expectations towards greater consumer involvement in health care decisions, this study investigates whether cancer patients have adopted a more authoritative stance within the consultation. Studies have reported that patients are indeed playing a more active part in the management of their illness, although few reach a consensus of what 'greater involvement' actually entails. Therefore, the issue of patient participation in the doctor-patient encounter still leaves room for further investigation. It has been reported by various authors that consumer dissatisfaction often stems from inadequate communication between the doctor and the patient (Korsch et al, 1968; Kessel, 1994; Razavi et al, 1997). The increase in medical litigation, especially in the USA, is often the consequence of poor communication and misunderstanding between the doctor and the patient. In cancer care the need to provide accurate and truthful information to the patient becomes particularly acute due to the risk of adverse psychological effects which can be triggered through communication problems. Thus, there is a need to identify those aspects of the communication process that will improve

patient satisfaction and well-being. This study illustrates not only how the communication process could be enhanced, but the 'strategies' that oncologists and colorectal cancer patients adopt to interpret complex information.

Investigating the communication process

Cancer is unique in comparison to many other conditions because of its life threatening nature and because it still arouses fear in the public at large. Also, the advantages and disadvantages of cancer treatment are often couched in uncertain terms which many patients find difficult to comprehend. Indeed, the language of 'probability' and 'risk' replaces the language of certainty. Many of the difficulties of clinician-patient communication stem from the uncertainties and ambiguities associated with cancer. The inability of modern medical science to provide clear answers to many of the questions surrounding the cancer diagnosis, has often led to difficulties in the communication task. The way that information is framed or presented to a patient can have a significant impact on his/her understanding of their condition as well as on their ability to make a treatment decision. The current study examines the impact of uncertainty on the patient's ability to interpret complex information, and how the process of information transfer affects the patient's understanding of their illness and treatment. Although research has shown that difficulties exist in the communication process between doctor and patient, little is known of how cancer patients make sense of probabilistic and statistical information. Some studies have begun to pay more attention to the way that patients interpret complex information (Charles et al, 1998), however a lot more research still needs to be done.

The exchange of information between doctors and patients has largely been investigated with cross-sectional studies, which have tended to focus on patients' views and reactions, rather than on the actual communication *process*. So although a lot has been published on patients' information preferences, very little empirical evidence exists on the actual doctor-patient interaction in the consultation during the vital stages of the decision-making task. This research evidence is particularly lacking in the study of cancer. Through observations of oncologist-patient interactions this study demonstrates not only the type of decision-making role that colorectal cancer patients prefer to play, but also the various roles that they adopt in the consultation with the oncologist during the important stages of the decision-making task. The observations also provide evidence of the role that oncologists play in the treatment decision-making process.

Why study cancer?

Medical knowledge in cancer is advancing at a rapid rate, which means that new treatments will introduce novel dilemmas of choice for patients. As clinical trials play an increasingly important role in the production of medical knowledge, the need to understand the impact that they have on the patient's role within the medical encounter is becoming ever more urgent. The treatment decision-making task in chronic illness is very different to acute illness, in the sense that individuals often have to cope with deteriorating health and often with the possibility of death. Thus, the decision-making task is often influenced by matters of life and death, and by issues which may not arise with individuals suffering with non-degenerative conditions. Although there is an equal need to understand the treatment choices that patients with acute illnesses make, recent medical progress in the treatment of cancer has provided fertile ground for research into the decision-making process.

Another reason why there is currently a pressing need to carry out research on the treatment decision-making process in cancer, is that it might cast some light on the impact of the recent changes in cancer care delivery which have been brought about by the recommendations set out by the Expert Advisory Group on Cancer in 1995 (Calman-Hine, 1995). The current study places the decision-making practices of patients and oncologists at the Bristol Oncology Centre, within the context of changing health care policy in cancer. To date, the treatment decision-making process in cancer has largely been investigated in isolation of the organisational and political changes affecting the delivery of cancer care. As a result, decision-making has been studied with little reference to its outside influences. This study, therefore, demonstrates not only the importance of understanding the changing organisational nature of health care delivery, but also the more immediate social context within which decisions are reached.

The Calman-Hine report recommended that cancer care should be delivered in specialist units or centres so that patients receive the best possible care. This way resources could be used more effectively by concentrating care in fewer units, thereby reducing the need for cross-referral of patients and the duplication of expensive treatments. The centralisation of cancer care could have direct implications for the decision-making process since treatment would only be available in select hospital units, and the decision to undergo cancer therapy could be affected by practical considerations. For instance, some patients may consider the inconvenience of travelling long distances on a regular basis to the treatment centre as a significant disadvantage to them. In addition, the current shortages in nursing and medical staff could lead to additional pressures as Cancer Centres are faced with greater patient numbers and increasing workload. The outcome of such a policy could be that patients may spend less time with their clinician, especially during the initial encounter, which could subsequently result in communication problems and possibly in

less patient involvement in the decision-making process. However, the overall care that patients obtain from specialist units could improve. The emphasis on multidisciplinary team-work by the Expert Advisory Group on Cancer also suggests that the care of patients will increasingly be co-ordinated by different teams (Calman-Hine, 1995). For instance nursing staff may assume more responsibility in communicating to patients and explaining to them the advantages and disadvantages of different treatment options. Thus, the decision-making process may be shared with different members of the 'team'. For instance, the management of patients at more advanced stages of their illness is currently carried out by clinicians as well as by palliative care teams. Thus, the greater emphasis on 'teamwork' could result in shared patient management initiatives, to replace consultant-led care which is currently practised.

The Calman-Hine (1995) recommendations also placed more emphasis on the importance of primary care teams in the management of cancer patients. The anticipated increase in the workload of Cancer Centres and Units could be reduced through the earlier discharge of patients and by increasing the role of GPs in cancer care. One potential difficulty with such a policy is that the costs incurred on patient care could be shifted to GPs, as well as the general burden of post-treatment follow-up. However, the issue arises as to whether GPs possess adequate expertise in the follow-up care of cancer patients. Studies have shown that early detection of recurrences are central to patient survival. Thus, closer liaison and communication between specialists and primary care teams will become increasingly important as GPs assume more responsibility for patient care. Indeed, some of the evidence that does exist suggests that the communication process between hospital specialists responsible for the care of cancer patients and GPs is deficient.

The treatment decision-making process is also being influenced by regional variations in resource allocation by purchasers. Currently, regional differences in the availability of certain cancer treatments have been attributed to the lack of a consistent policy in the setting of priorities, and to the unavailability of useful comparative data. As a result different purchasing authorities have been unable to compare their resource allocation decisions with those of other purchasers, which has led to geographical variations in the availability of certain treatments. To this extent, the decision-making task for the doctor and the patient will be directly shaped by the treatment options that are on offer. Thus, there is clear potential for conflict within the decision-making process in cases where the patient may be unsatisfied with the treatment choice that is presented to him or her.

The changing nature of the contracting relationship between purchasers and providers provides yet another reason to study the decision-making process within the context of current health care policy. The pressure on providers to spend within the available resources and demonstrate cost-effective use of their resources, has paved the way for evidence-based medicine. Providers are increasingly using research based evidence to justify their spending plans and to demonstrate the

appropriate use of resources. Also, clinical decision-making in cancer is often guided by research evidence, which means that the nature of decision-making is undergoing an important change, since clinicians are increasingly expected to justify their treatment decisions to purchasers as well as patients. The current study demonstrates how some of these organisational changes affect the process of decision-making between oncologists and colorectal cancer patients.

Why choose colorectal cancer?

Research on the decision-making practices and information needs of patients with colorectal cancer is limited. Most studies in this area have been conducted on breast cancer, or on the views of patients with different diagnoses. Furthermore, many of the studies have limited their focus on patients with early or stable disease, and therefore, there is a lack of sufficient data that enables comparison between the decision-making practices of patients with early as well as advanced disease. In response to this, the current study explores the decision-making and information preferences of colorectal cancer patients at different stages of their treatment cycle and at different stages during the illness experience.

Although breast cancer is the third most common cancer in the UK, colorectal cancer is the second most common cancer in both men and women. Given the high incidence of this disease the general public still have very little understanding of the factors which may contribute to its development, or which symptoms to look out for. On the other hand, breast cancer has received a lot more media and research attention, and women are more aware of the common signs of the disease. However, people are less aware about colorectal cancer and able to identify the early onset of the disease. The difficulty in the early diagnosis of colorectal cancer is perpetuated by the common symptoms that it shares with other bowel conditions such as irritable bowel syndrome, ulcerative colitis, and Crohn's disease. For this reason it is more difficult to diagnose, and individuals are less likely to present to their doctor at an early stage. Also, there is a misguided public perception that bowel cancer tends to affect mostly men. However, approximately equal numbers of men and women are diagnosed with the disease each year. This lack of public knowledge about colorectal cancer is often reflected in the consultation, where patients are less aware of the treatment options that are available to them. In contrast, women with breast cancer are much more aware of the treatment options that they can expect to be offered by their specialist. The study examines how this low level of public knowledge might affect the decision-making practices of patients with colorectal cancer.

As indicated above, much of the research conducted in treatment decision-making has focused on patients with breast cancer, where the proportion of patients occupying the younger age groups is higher than amongst those patients who have colorectal cancer. The majority of patients with colorectal cancer tend to be aged over sixty. Thus, this study investigates the decision-making practices and information needs of patients who generally are older than those with breast cancer. This will cast some light on the views and opinions of older cancer patients who have been given relatively little research attention in recent years. In addition, the choice to investigate the decision-making practices of patients with colorectal cancer facilitates a comparison between the perceptions of men and women. The extensive attention that has been paid to breast cancer in recent years has overshadowed the need to examine the views and preferences of cancer patients of both sexes.

Using qualitative methods

Most studies investigating the decision-making *process* in cancer have tended to use structured research instruments. These studies were largely concerned with understanding patients' treatment choices when faced with several competing treatment options. Also, they rarely attempted to investigate the *process* of decision-making as it happened in the consultation, nor the social context which might have affected the decision-making task. The main reason why these factors received little research attention in the past is because studies were largely concerned with general issues, such as whether patients wanted greater or less involvement in decision-making.

The current study uses qualitative research methodology in order to explore the process of treatment decision-making and assess what part social issues play in cancer patients' decision-making behaviour. In-depth interviews and observations of oncologist-patient interactions provide evidence of what patients said, as well as what they actually did in the consultations. In addition, follow-up interviews were conducted after five months with the original group of informants, as well as with oncologists, nurses and managers at Avon Health Authority. This data not only provides a longer-term view of patients' perceptions of the decision-making process, but also the views of health care workers, medical and other health authority staff, about wider issues surrounding the organisational changes facing cancer care delivery.

Observations of interactions between oncologists and patients presenting for the first time provide rare data of the dynamics inherent in the decision-making task within the setting of the consultation. Thus, the evidence that is presented in this thesis is not just based on retrospective accounts of doctors and patients, but on observation notes of consultations that were recorded

verbatim. The interpretations of the decision-making encounter are based on direct observations. Such information provides a unique insight into how decisions are reached between oncologists and patients with colorectal cancer. The main reason why notes were initially recorded verbatim was so that all subsequent analyses and interpretations could be placed within the context of the original dialogue that occurred between the oncologist and the patient.

Whereas the observations provide a cross-sectional view of how decisions were made within the consultation, the in-depth interviews provide a snapshot of how informants perceived the decision-making process. The in-depth interviews also placed patients' decision-making and information preferences within the wider context of their everyday lives. This way, informants' decision-making behaviour could be examined with reference to social, as well as to clinical and scientific attributes. Cancer patients often make treatment decisions, which are based on social factors, such as whether transport or family support is available. However, much of the research has paid limited attention to the role of social factors in decision-making. In-depth interviews can provide data, which reveal the complexities involved in the decision-making *process*, in this case as perceived from the patient's point of view. Studies adopting more structured designs are less able to explore the intricate processes involved in decision-making. For instance, they may be unable to identify as effectively as in-depth interviews, the way that patients' information preferences change during different points in the illness trajectory. For this reason a qualitative research design was adopted for the current investigation.

The implications of treating Bristol as a case study

The Bristol Oncology Centre is a tertiary referral centre in the South West region. The Centre provides treatment for most of the common cancers such as breast, colorectal and lung cancer, which makes it a suitable setting for the recruitment of patients presenting for the first time. Also, oncologists at the Oncology Centre specialise according to cancer site. Consequently, patients with specific cancers can be recruited from one oncologist specialising in a particular site, rather than from a number of different specialists. Thus, the concentration of care within one setting makes recruitment more practical and efficient. A smaller department would not receive as many referrals as a large centre, which in-turn could lead to the slower recruitment of patients. A large cancer centre such as Bristol receives referrals from a wide geographical area for various sites and stages of cancer. As a result there is a greater opportunity to recruit a more heterogeneous group of patients for the study. This has implications for conducting clinic observations, as the large patient throughput provides the opportunity to conduct a greater number of observations.

Most studies investigating the cancer patient's role in treatment decision-making have tended to focus on surgical rather than oncological treatment options. Thus, the presence of the oncology centre in Bristol provided an ideal opportunity to explore how decisions were made regarding chemotherapy and radiotherapy treatment, an area which has been largely under researched.

One clear advantage of treating the Bristol Oncology Centre as a case study, is that the individuals who attend a large regional cancer centre, are more likely to be representative of different geographical and social groups than those attending a smaller department. Thus, the patients who are recruited for the interviews are more likely to express diverse views and opinions. Clearly, the advantage being that the colorectal cancer patients in the current study could be expected to reflect the views of patients attending cancer centres comparable in size and patient numbers.

There is also the opportunity for studying organisational changes affecting the Bristol Oncology Centre, which have been initiated by the recommendations of the Expert Advisory Group on Cancer in 1995 (Calman-Hine, 1995). Bristol has attracted media attention in recent years which has led to extensive debate in the national press raising the issue of quality and equity of cancer care. The organisational changes facing the Bristol Oncology Centre provide an important context within which treatment decision-making and the doctor-patient communication process can be investigated. As a result of the Calman-Hine recommendations, cancer departments are expected to deliver cancer care in more centralised units or centres, where the ultimate goal is to provide specialist care to patients. The concentration of cancer care in specialist centres is likely to increase patient numbers because patients might be more aware of specialist treatment, and GPs may be encouraged to refer their patients to receive the best possible service. However, very little is known of the possible impact of the centralisation of cancer care on the doctor-patient encounter, and ultimately on the decision-making task. Greater patient numbers could result in a shorter consultation time, and doctor-patient communication might be restricted in order to increase patient throughput. Indeed, some research evidence exists that an increase in patient numbers could lead to the earlier discharge of patients.

In addition, the increasing emphasis on 'evidence-based medicine' in making treatment decisions, might lead to difficulties for clinicians in trying to communicate scientific information to patients. Certainly, this study shows that the oncologist-patient communication task has become more challenging both for the clinician and the patient. The routine use of probabilistic information within the consultation is due to the greater dependence on scientific evidence by clinicians. This stems from the dramatic increase in clinical trials in recent years, as well as the ensuing pressure on hospital specialists to account for the treatment decisions that they make. Thus, clinicians are facing the need to account for their decisions to purchasers as well as to patients. The recent policy changes taking place in cancer care provide a context within which to

assess the treatment decision-making task. Moreover, the Bristol Oncology Centre is an example of how cancer care will be organised in future years.

Conclusion

The subsequent chapter 2 provides a review of the literature on treatment decision-making in cancer and on the information needs of patients with cancer. The following chapter 3 outlines the research methods that were adopted in the study. Chapter 4 illustrates the general approach that was adopted in the analysis and interpretation of the interview and observation data. It also shows how the data were subjected to checks of consistency, authenticity, and rigour. Chapter 5 describes the characteristics of the patient population. Chapter 6 provides a discussion of the policy issues in cancer treatment and chapter 7 presents the results and interpretation of the interview and observation data. Firstly, the main research findings relating to treatment decision-making are provided. This is followed by an examination of the current policy and organisational changes affecting cancer care delivery, with reference to the interviews carried out with members of staff at the Bristol Oncology Centre and Avon Health Authority. The final chapter provides a discussion of the main research findings within the context of current research evidence and explores their implications on future health care policy. Finally, some recommendations for further research in cancer decision-making are proposed.

CHAPTER 2

DO PATIENTS WANT PARTICIPATION OR INFORMATION? AN EXPLORATION OF THE EVIDENCE WITH SPECIAL REFERENCE TO TREATMENT DECISION-MAKING IN CANCER CARE

Introduction

This chapter is divided into three main parts. The first part of the chapter reviews the background literature on colorectal cancer, including treatment options and treatment variations. The second part explores the main models of the doctor-patient relationship as reported in the literature. Issues relating to the nature of the doctor-patient interaction and the different communication styles are reviewed. An evaluation of cancer patients' information needs and the factors that influence the exchange of information is presented. Doctors and patients often share different 'world views' and many of the problems experienced in the medical encounter stem from their different perspectives. However, much of the recent research evidence shows that patients are demanding a greater input in the consultation. The third and largest part examines the research evidence on treatment decision-making in colorectal cancer. It addresses whether cancer patients want to be involved in treatment decision-making, or whether they just prefer to be well informed. This part also explores the factors that affect the treatment decision-making process. For instance, the extent to which psychosocial, clinical, cultural, and physician-related factors affect the decision-making process are assessed with reference to the recent research evidence. The review concludes with a section exploring some methodological issues that were raised during the course of reviewing the research evidence.

Part I: Background and the current literature on colorectal cancer

There are a quarter of a million new cases of cancer registered in the United Kingdom, and 160,000 people die from the disease each year. Lung and colorectal cancer account for 28% of all cancer diagnoses in the United Kingdom per year, with colon and rectal cancer being the second most commonly diagnosed cancer, representing between 11% and 15% of all cancer diagnoses, with breast cancer representing 10% of all new diagnoses (Fallowfield, 1990). However, whereas the average five year survival rate in 1981 for breast cancer stood at 62%, the figure for colorectal cancer was 37% (Cancer Research Campaign, 1988).

The clinical research literature on colorectal cancer is voluminous, and thus, it would be impossible to review most of it in this chapter. Much of the research conducted on colorectal cancer has largely been based on clinical studies and randomised controlled trials. Most of these studies are concerned with the testing of different chemotherapy regimens, and various surgical procedures on tumour response and survival. Thus, much of the research carried out has examined the effect of treatment on disease-state and patient survival, rather than on patient preferences. In fact, only a very small number of studies identified in the social science and medical literature sought to investigate the process of doctor-patient decision-making in colorectal cancer.

Another large area of literature on colorectal cancer has focused on the impact of screening programmes on disease detection, and the economic implications of mass screening. Further, a large volume of research has also been conducted on psychological and psychosocial factors in screening for colon and rectal cancer. This body of research provides some insight into the public's perceptions of colorectal cancer, but very little research has so far been conducted on patients' involvement in the treatment decision-making process.

Treatment options

The extensive research that has been conducted on the effectiveness of surgical resection and chemotherapy on colorectal cancer has resulted in a consensus on the best way to treat patients. Thus, the emphasis has mainly been on disease behaviour, rather than on patient behaviour. Many clinical studies have found that surgical resection of colon and rectal tumours is the most

important determinant of survival and future outcome (Cady et al, 1998; Violi et al, 1998). Indeed, as one study reported, routine post-operative follow-up increased the survival of patients, since earlier detection of recurrence resulted in earlier treatment and improved survival (Bergamaschi and Arnaud, 1996). In addition, extensive research has shown that adjuvant chemotherapy for Duke's C colorectal cancer improves survival benefit. However, drug treatment has not shown any benefit for patients with early stage cancer, Duke's A and B (Casillas et al, 1997; Labianca et al, 1997; Parshad, 1997; Rougier and Neoptolemos, 1997; Vaughan and Haller, 1997; Zaniboni, 1997; Wils, 1998; Bleiberg, 1998). This evidence indicating the benefit of chemotherapy treatment for Duke's C colorectal cancer, coupled with the reported benefit of complete surgical resection, is the main reason why most patients are currently managed by a combination of surgery and drug treatment. In contrast, patients with 'early' disease are often managed with surgery alone. However, although the research literature suggests the optimal means of treating patients, very little empirical evidence exists to demonstrate whether patient management conforms to, or deviates from, this gold standard in practice.

Patients with colorectal cancer have a 40% chance of developing recurrences and dying from the disease, which is why a large proportion of patients will face having to decide whether to undergo further treatment for their disease (Labianca et al, 1997). Thus, the importance of post-treatment follow-up is especially acute in the management of colorectal cancer. However, the research evidence about the benefit of follow-up is somewhat contradictory. For instance, one study comparing routine with non-scheduled follow-up of patients after undergoing 'curative' surgery for colorectal cancer, found that routine follow-up improved the survival of patients as compared to those attending for a non-scheduled visit (Bergamaschi and Arnaud, 1996). A review reporting the evidence of post-treatment screening though, found that follow-up screening programmes have not reduced overall mortality from colorectal cancer (Nelson, 1993). Other studies indicate that early detection of asymptomatic recurrences in patients with colorectal cancer can improve survival in offering the option of surgical resection of liver metastases. However, more advanced recurrences in the liver cannot be resected surgically, and often lead to a worse prognosis (de Goede et al, 1998).

Variations in the management of colorectal cancer

Most of the research conducted on colorectal cancer has been conducted in the medical setting, and as a result much of the literature reviewed in this section will have a strong clinical leaning. It may therefore be inevitable that the dominant decision-making model in colorectal cancer, as identified in the literature, will be biased towards the clinical paradigm. In addition, only a small

volume of research has been carried out in the social sciences on treatment decision-making in colorectal cancer. This suggests that the predominant concern of existing investigations has leaned towards studying the management of disease, rather than the management of the patient.

The research evidence suggests that marked geographical and clinical variations exist in the management of patients with colorectal cancer. These variations are reported to be the product of different treatment protocols and practice styles of cancer specialists (Mushinski, 1998). One study investigating the post-operative complications and survival of 645 patients following surgery conducted by 13 general surgeons in one hospital, reported that wide variations exist in post-operative mortality and survival. None of the surgeons who performed an operation had a specialist interest in colorectal cancer, and the authors concluded that greater site specialisation in the surgical treatment of colorectal cancer is likely to improve survival and post-surgical morbidity (McArdle and Hole, 1991). Another study also found wide variations in the proportions of patients receiving an anterior resection, an 'AP' resection, and a colostomy (Pollock and Vickers, 1997). This study also reported that patients presenting for elective surgery were more likely to be treated by a consultant than those presenting on emergency. All these factors were thought to contribute to the wide variations in the management of patients.

There are also wide geographical variations in resource utilisation for the management of patients with advanced colorectal cancer. One study found that although the approach to patient management in different countries was similar, resource utilisation showed wide variation both within and between countries (Torfs and Pocceschi, 1996). A similar study conducted on all cases of colorectal cancer registered in 1987 in eight European countries, found that surgical resection declined with advancing age, suggesting that older patients were less likely to receive 'curative' surgery. Thus, access to surgery and endoscopy may contribute to the large inter-country survival differences (Gatta, et al, 1996). Similarly Herbert et al (1995) found huge geographical differences in the participation rate to a mass screening programme. People attending a GP practice in France were invited by the GP to take part in a screening programme for colorectal cancer. People who lived in rural areas were much less likely (27.7%) to participate in mass screening, than people living in urban areas (65.5%). However, the study reported no effect of age or sex on level of participation. It is anticipated that the lack of awareness of individuals living in rural areas about colorectal cancer services, could partly explain the low adherence to screening in this group of people. However, more research still needs to be conducted to assess why some people are unwilling to be screened for colorectal cancer.

There is also age-related variation in the management of colorectal cancer. One study carried out in New Mexico for instance, found that the non-receipt of surgery for colorectal cancer was positively related to older age, and also the non-receipt of radiotherapy treatment was strongly related to restricted access to transportation. This finding indicates that the variation in the provision of cancer treatment is related to non-medical factors such as older age and limited

access to personal transport (Goodwin et al, 1995). Colorectal cancer represents 15% of all cancer diagnoses, two thirds of which are found in the over 65 year olds, and 40% of these patients present with advanced disease (Fallowfield and Clark, 1994). In colorectal cancer, surgical resection offers the only hope of cure, or palliation, for those with advanced disease. Some studies have indicated that the age of the patient should not by itself interfere with the decision to offer curative surgery, since significant reductions in morbidity and mortality are achieved through surgery in older patients (McGinnis, 1994). Other studies have also found that older patients should be offered surgery for metastatic disease, as surgery carries no additional survival risk (Koperna et al, 1998). However, the research evidence tends to support the view that elderly patients should be carefully selected for surgery in order to minimise post-operative mortality and morbidity, which does increase with age (Violi et al, 1998).

Other studies have reported racial differences in survival from colorectal cancer. For instance, an important study conducted in the USA on Medicare beneficiaries who were 65 years of age or older, found that patients from ethnic minorities were less likely to undergo surgical resection than 'White' patients (68% versus 78%, (Cooper et al, 1996)). The study also found that 'White' patients had a more favourable mortality rate than 'Non-Whites' (two-year mortality rate of 40% versus 33.5%). These disparities were similar in teaching and non-teaching hospitals, as well as in private and public hospitals. The study concluded that these differences in survival and access to treatment stemmed from wider racial inequalities in society.

Another American study also found that 'Non-White' patients with colorectal cancer were more likely to be hospitalised with more advanced conditions, and treated less aggressively than 'White' patients. The authors concluded that this was the result of previous poor medical management (Ball and Elixhauser, 1996). However, differences could also indicate that 'Non-White' patients presented with more advanced disease, which is why more were hospitalised and why less aggressive treatment may have been more appropriate than aggressive treatment. Nevertheless, this issue was not explored by the investigation. A similar study in the USA reported that large variability in colon cancer incidence and mortality exists between counties for both 'White' and 'Non-White' populations, suggesting differences at the county level in screening and treatment (Cooper et al, 1997). Furthermore, the study concluded that the consistent racial disparity within different counties reflected overall inequalities in access to and quality of care for 'Non-White' patients.

Racial differences in health care utilisation have also been reported to reflect wider socio-economic inequalities. Thus, some studies suggest that patients diagnosed with colorectal cancer who live in economically deprived areas are more likely to be diagnosed with late stage disease than individuals living in areas with higher socio-economic status. People living in socially deprived areas may have restricted economic means which could prevent them from consulting a doctor earlier than people who have better economic resources at their disposal. Thus race may

not be the only determining factor in poor health care utilisation patterns. In addition, economic deprivation is important where information about the importance of screening and early presentation may be communicated ineffectively. As a result of this finding, a case could be made for targeting screening for socially disadvantaged groups (Mandelblatt et al, 1996). Other studies found no differences in patient survival according to whether they used a fee-for-service, or a state funded health care plan (Vernon et al, 1992). However, this finding may not be surprising given that patients who have private or state funded insurance plans, often receive the same care and consult the same specialists.

In conclusion, many of these studies show that wide variations exist in the treatment of patients with colorectal cancer. Racial and socio-economic variations in treatment indicate that more effort is required in delivering information more effectively about the benefits of early detection of colorectal cancer. Individuals living in areas of high socio-economic deprivation may not be aware of the symptoms to look out for, and as a result may present late. There are also marked differences in the way older patients with colorectal cancer are treated compared to younger patients, who tend to receive less 'curative' treatment. This is somewhat surprising considering that two thirds of patients with colorectal cancer are older than 65 years (Goodwin et al, 1995). In addition, there is evidence of wide, practice based, variation in the management of patients. Thus, there is a need to streamline the way services are delivered, and much more emphasis should be placed on surgical site-specialisation in order to maximise the benefit of treatment for patients.

Public perceptions of screening for colorectal cancer

New advances in treatment for colorectal cancer have led to improvements in patient survival, signalling the potential benefits of prevention and screening. Consequently, a large volume of research has been conducted on the advantages and disadvantages of screening for colorectal cancer. In this section, some of the reasons for patient participation and non-participation in screening programmes is assessed.

Screening for colorectal cancer can involve one of four possible options: faecal occult blood testing, flexible sigmoidoscopy, barium enema, and colonoscopy. This contrasts with screening for breast cancer which commonly involves undergoing a mammogram scan. In addition, the level of awareness surrounding breast cancer screening is by far higher than it is for colorectal cancer. Consequently, the lack of public knowledge about the possibility of screening for colorectal cancer is one reason why the demand for this service has not been as great as it has been for breast cancer over the last one or two decades (Thomas and Clarke, 1998).

The lack of public awareness of screening options for colorectal cancer was reflected in one American study investigating patient preferences for screening (Leard et al, 1997). The study found that although 96% of the subjects who were selected randomly from GP practice lists, wanted to be screened, they did not indicate a preference for any single test. This suggests that most study respondents were not aware of the differences between the various tests that were available, which indicates that information about screening for colorectal cancer has generally not reached the public effectively. A further study assessed the effectiveness of a health education leaflet in informing members of the population about screening for colorectal cancer (Hart et al, 1997). One hundred subjects were interviewed before and after reading the leaflet. It was found that the number of men stating that bowel cancer was 'very common', increased dramatically from 20% to 60% after reading the leaflet, and this number increased from 30% to 70% for women. After reading the leaflet, 55% of men who initially refused screening reversed their decision. The most common reason given by subjects for declining the test was that they felt well in themselves. This finding suggests, once again, that people in the general public do not perceive a great need to undergo screening for colorectal cancer, presumably due to the low public profile that colorectal cancer has been given (McGinnis, 1994; Donovan and Syngal, 1998; Labianca et al, 1997).

It has been reported that substantial variation exists in patients' attitudes towards screening for colorectal cancer (Dominitz and Provenzale, 1997), which can partly be explained by personal characteristics such as gender, age and family status (Redmond, 1998). Several authors have stated that the success of a screening programme depends not only on the effectiveness of the screening techniques, but also on the willingness of people to be screened. If compliance is small then the resources which are employed in detecting cancer may not be justified. Some studies have found that members of the general public do not want to undergo screening, and the most important determinants of peoples' willingness to participate in screening programmes are a family history of colorectal cancer, a belief that bowel cancer can be cured if detected early, and a perception of personal susceptibility to bowel cancer (Weller et al, 1995). However, caution must be exercised when drawing conclusions from predictive studies of peoples' willingness to undergo screening. Firstly, many studies that are conducted are general population studies which do not distinguish between individuals with and without a family history of colorectal cancer. People with a family history may be more willing to undergo screening, and therefore, studies must make this distinction when reporting results of peoples' desire to be screened. Secondly, since most studies are conducted on people in the general public, it is necessary for future studies to draw a distinction between those individuals who take the decision to be screened and those who simply state their intention to do so. Socio-demographic and cultural factors such as age, gender, and race, can influence an individual's decision to participate in a screening programme also (Hebert et al, 1997).

Women are particularly vulnerable to colorectal cancer because they are less likely to undergo screening believing that bowel cancer is more common in men, and their desire to avoid discomfort of some of the screening techniques such as sigmoidoscopy which is a particularly invasive procedure (Donovan and Syngal, 1998). In addition, GPs may not always be aware of the most recent screening technologies, so that the numbers of people who are made aware of the possibility of screening is relatively low.

Colorectal cancer is a good candidate for mass screening because it is the second leading cause of cancer mortality in the UK and the USA. It also develops slowly and several methods of early detection are available. It has been estimated that annual testing for faecal occult blood and sigmoidoscopy every five years could result in a 40% decrease in colon cancer (Byers and Gorsky, 1992; Byers et al, 1997). One study has also predicted that projections of colorectal cancer trends to the year 2000 indicate major expected rises in incidence and prevalence of the disease (Capocaccia et al, 1997). However, the main reasons why screening is not universally part of the decision-making process, is that efficacy in terms of the costs and benefits have not yet been fully assessed. Many studies have reported that assessment of mass screening programmes is very time consuming and costly, and accurate data from clinical trials will take time collect (Byers and Gorsky, 1992; Nelson, 1993; Weller, 1995).

Psychological responses to treatment and screening

Patients with colon and rectal cancer experience a significant amount of psychological morbidity due to the sensitive location of the cancer site. As a result patients often feel embarrassed to talk about problems relating to bowel movement and rectal bleeding, and are often reluctant to undergo screening, especially older patients. Consequently, a reasonable amount of research has been carried out on the psychological responses of patients to cancer therapy and their quality of life (Decossee and Cennerazzo, 1997; Dominitz and Provenzale, 1997; Ulander, 1997; Whynes and Neilson, 1997; Anderson and Palmer, 1998). One study found that 30% of the study population who were surveyed stated embarrassment as the main reason why they declined screening (Schraub et al, 1995). The study also found that the fear of cancer as a disease, the fear of a cancer diagnosis, and anxiety about the possible therapeutic consequences, were the major determinants of refusal to undergo screening for colorectal cancer. Increasing public awareness of the disease may reduce the fear which people have and increase compliance to screening programmes.

Many of the studies conducted on colorectal cancer have tended to examine the contributory factors to psychological morbidity, and the ways in which psychological stress can be minimised. The follow-up of patients, who have undergone surgical resection for colorectal cancer, has been shown to reduce anxiety levels (Graupe et al, 1996). The follow-up may serve an important therapeutic role for patients, perhaps offering the opportunity to discuss problems with the doctor, and thereby reducing any uncertainty, which might be felt following treatment.

Some studies have sought to examine the impact of chemotherapy on patients' psychological morbidity, on the presumption that chemotherapy in itself is a source of great distress to cancer patients. One study compared the psychological distress scores of colorectal cancer patients who were either given a chemotherapy regimen, or were assigned to a 'non-intervention' programme following their surgical resection. The study reported that patients receiving chemotherapy had similar psychological distress scores as those having no chemotherapy (Norum, 1997). This finding suggests that chemotherapy treatment does not have a significant impact on patients' psychological morbidity. However, a different study investigating the level of psychological distress of 66 patients three months following their initial diagnosis of colorectal cancer, found that having additional treatment (chemotherapy) contributed to higher levels of functional dependency. Thus, patients' initial psychological trauma resulting from a cancer diagnosis and initial surgery, could have prevented them from functioning in their usual roles (Barsevick et al, 1995). However, the study only investigated the psychological adjustment of patients three months following their diagnosis, and a longer term investigation could have identified psychological morbidity caused by chemotherapy more effectively. Thus, additional longer-term studies need to be carried out to gauge more accurately the extent to which patients adjust to their illness and treatment.

Another study investigating the impact of surgery on patients' psychological status, found that pre-treatment symptoms of psychological distress had dissipated after three months, suggesting that they were more likely to have resulted from the anticipation of treatment rather than from the disease itself (Whynes and Neilson, 1997). This finding further supports the hypothesis that patients with colorectal cancer adjust to their cancer diagnosis in time. However, other studies have clearly shown that patients with colorectal cancer experience depressive symptoms as a result of surgical resection of their cancer (Orsi et al, 1996). One study also found that patients with a stoma, and those without, suffered the same level of psychosocial problems four years following surgery (Bekkers et al, 1997). This indicates that patients might suffer greater psychological problems of adjustment as a result of surgery or their diagnosis, rather than due to the presence of a stoma. Other studies have also indicated that surgery for rectal cancer can result in significant loss of sexual function, and as a result there is a greater need to monitor the psychological health of patients undergoing such procedures (Audisio et al, 1997). Also, the need

to involve patients with rectal tumours in the treatment decision-making process may help to reduce the psychological distress experienced following invasive surgery for rectal cancer.

Summary

This Section has demonstrated that so far the research pertaining to colorectal cancer has focused on clinical aspects of the disease, issues associated with screening, and psychological morbidity. The few studies which have investigated the treatment decision-making process in colorectal cancer, have demonstrated a need for patients to become involved in deciding on their treatment. One study investigated the desire of colorectal cancer patients to become involved in deciding whether to accept or refuse entry into a chemotherapy trial (Llewellyn-Thomas et al, 1991). Although the decision to enter into the trial was only hypothetical, twenty-five patients claimed that they would agree entry into the trial, and thirty-five would refuse. The 'refusers' demanded more participation in decision-making, and indicated that the main reason for refusal was aversion to 'randomisation'. This study indicates that many patients with colorectal cancer want to have some control over the decision-making process. Some studies have in fact found that cancer patients prefer to have some control over decision-making as a means of maintaining a positive outlook (Mackillop et al, 1988).

Another important study found that colorectal cancer patients with advanced disease tended to over-estimate their chances of survival, which in turn affected their treatment choice (Weeks et al, 1998). For instance, most of the patients who thought that they would live for six months or longer, counter to clinical opinion which predicted a much shorter survival time, opted for aggressive life-extending therapy. Patients who believed that they would not live very long chose comfort care. However, the patients who chose life-extending therapy and those who selected comfort care had the same six-month survival rate. This study strongly indicates that many patients with colorectal cancer have an inaccurate perception of their prognosis, which directly affects their treatment decision. Given that the study reported no difference in the six month survival between those choosing life-extending treatment and comfort care, patients who opted for the former suffered unnecessary treatment side effects which could have been avoided if they had a more accurate understanding of their prognosis. The findings of this study support those of other similar investigations indicating that in situations of uncertainty, individuals tend to 'dichotomise' probabilistic and prognostic information. (Parsons and Atkinson, 1992; Redelmeier et al, 1993; Charles et al, 1998). However, the specific social and cognitive processes which lead

to the polarisation of information are still unclear. Although, the need for patients to feel hopeful about their future may be a strong incentive for being optimistic. These issues will be returned to in greater detail in part III.

Part II: Doctor-patient interaction

Models of the doctor-patient relationship

The doctor-patient relationship has been represented by four theoretical models since the 1950's: the consensus, conflict, negotiation, and patient participation models. Talcott Parsons (1951) provided a 'consensus' model for the doctor-patient relationship, reflected in his 'sick role' concept, in which the roles of the doctor and the patient are mutually reinforcing. For instance, both the doctor and the patient share the expectation that patients should seek the doctor's help and advice in an effort to aid the patient back to recovery. Quill (1983), however, claimed that the doctor-patient relationship is 'consensual' rather than obligatory, in that the patient and the doctor both share the view that the patient should be aided in his/her recovery from illness. On the other hand, Freidson (1970) realised that doctors and patients inhabited different cultural, social, and economic worlds which could lead to conflict. Some have referred to this difference as 'incommensurability' (Veatch and Stempsey, 1995). Various representations of such conflict were provided by different researchers. Waitzkin (1979) for instance, attempted to draw links between the micro-world of the doctor-patient encounter, to the wider repressive structures of capitalist society.

Just as the 'consensus' approach did not represent adequately the form of the doctor-patient encounter, the 'conflict' model failed to reflect the dynamic nature of the doctor-patient interaction. According to the two models, the doctor-patient relationship is either in a state of conflict or consensus, where a middle ground does not appear to exist. Tuckett et al (1985) however, in their study of general practice consultations, found that many interactions involved some negotiation between the doctor and the patient. The authors found that communication difficulties existed in the consultations. However, this was the result of a lack of mutual exchange, rather than the presence of conflict (Bury 1997). Thus, conflict was a rare feature of the doctor-patient relationship in this study.

In recent years, there has been growing pressure on the medical profession to facilitate greater patient involvement in the doctor-patient relationship. This pressure has come from various

consumer pressure groups, and the need for the medical profession to safeguard itself against possible litigation (Gray and Doan, 1990; Williamson, 1992; Laine and Davidoff, 1996). As a result, the research focus has shifted from an interest in patient satisfaction, to investigating the nature of patient participation in the consultation (Speedling and Rose, 1985; Sutherland et al, 1991; Thomsen et al, 1993; Weil et al, 1994). Certainly, some authors even advocate a style of discourse where the power balance is shifted in favour of the patient, and where the doctor only provides an information service (Williamson, 1992). Such models support an unequal relationship between the doctor and the patient, in which the patient makes the decisions. However, other authors have criticised this approach, since it does not recognise the possibility that many patients, in fact, prefer a more paternalistic relationship with their doctor (Arnason, 1994). Such a model also does little to promote a reciprocal communication style, during which the patient could profit from the doctor's advice. Thus, the move from a therapeutic relationship which is highly paternalistic, to one which focuses entirely on patient preferences, fails to consider the importance of reciprocity and negotiation between the doctor and the patient in the current health care system (Abramovitch and Schwartz, 1996).

Patient participation in the doctor-patient encounter

The above studies indicate that many of the problems which arise between the doctor and the patient stem from inadequate communication. An important reason why such problems occur more frequently in the consultation, is that the boundaries of what type of information patients should receive, have recently become somewhat blurred (Mathews, 1983). One way in which this problem has been addressed is through encouraging greater patient involvement in the interaction with the doctor, so that patients can become more active in deciding what information they require (Henbest and Stewart, 1990; Simpson et al, 1991; Delbanco, 1992; Pietroni and Chase, 1993; Golin et al, 1996; Laine and Davidoff, 1996). According to Epstein et al (1993) there is a growing need for physicians to find a common ground with patients regarding the management of care, by recognising that the meaning of illness for the patient can have an important bearing on the full understanding of the clinical problem.

Some studies indicate that outcomes can improve through greater patient participation, since patients who are encouraged to participate have an increased sense of control. This may in turn help them to take part in behaviours which are health-maintaining (Korsch et al, 1968; Deber, 1994). For instance, Cassileth et al (1980) found in their study that those patients who wanted to be involved in treatment decisions were more hopeful than those who did not. A study by Henbest

and Stewart (1990) also found that when the doctor facilitated patient participation, by helping the patient to express thoughts, feelings and expectations about their management, their outcomes improved. Other studies also show that patients want to participate in the doctor-patient interaction (Stewart, 1984; Botelho, 1992; Delbanco, 1992; Dunsmore and Quine, 1995). However, many of these studies were conducted in general practice, where patients might be more familiar with their complaints, and more willing to participate, than other patients with more serious complaints. Also, many of these studies have not defined what they meant by 'participation'.

Other studies found that a cancer diagnosis had a significant impact on patients' level of participation in the doctor-patient interaction, and on the extent to which they became involved in decision-making and 'problem-solving' (Risko et al, 1996; Silliman et al, 1998). The authors concluded that psychological counselling and guidance was very important during the first interview with the cancer specialist in helping patients come to terms with their diagnosis and in enabling them to participate more effectively in the future management of their condition.

Barriers to patient participation in the doctor-patient interaction

Doctor-patient interaction in cancer care is an under researched area. Few studies conducted on cancer have provided evidence that patients are becoming more involved in the interaction with their specialists. In fact, many studies report that various communication barriers prevent doctors and patients from establishing an effective dialogue. Siminoff et al (1991) found in their study that oncologists tended to initiate most discussions, and emotionally charged issues were rarely discussed between the doctor and the patient. Ford et al (1996) similarly found in their study of consultations between oncologists and cancer patients, that interactions were dominated mostly by the concerns of the oncologist who kept to a rigid biomedical agenda. Clinicians did not pursue many psychosocial issues with patients indicating that emotional concerns were largely left unexplored. This was one of a few studies that have investigated the spoken dialogue between the doctor and the cancer patient within the consultation. It also provides unique evidence on the content of a consultation with the newly referred cancer patient. However, participants had different cancer diagnoses and the content analysis used in this study does not take into account each patient's diagnosis, disease stage or psychological circumstances. For instance, some patients may not have wanted to, or were unable to play an active part in the consultation with their

doctor. Thus, the study does not attach great significance to the context of the consultation in affecting the patient's ability to participate in the interaction.

It has also been reported that structural constraints often affect the doctor-patient communication process. For instance, the limited time allocated for discussion with patients during ward rounds was a major factor restricting the ability of patients to ask questions of doctors in one study (Meredith, 1993a: 1993b). Instead, communication with patients was subordinated to the need to accomplish the required throughput, whereby surgeons interpreted the function of the consultation as diagnostic and technical, rather than communicative. Another study also found that short interactions prevented patients from asking questions of their doctors whereas longer interactions fostered information seeking behaviours (Reynolds et al, 1981).

Patient satisfaction with health care has also been linked to the doctor's ability to decode a patient's non-verbal communication, such as the emotions expressed through bodily movements, body posture and facial expressions (Dimatteo et al, 1979). Further, there is a need for clinicians to express empathy, listen, convey positive regard and instil hope when communicating with cancer patients (Roberts et al, 1994). Two studies have shown that patients who felt that the doctor understood their concerns were more likely to be satisfied with the care which they received (Korsch et al, 1968; Blanchard et al, 1990). However, most patients in these studies felt that their concerns were not met. These findings strongly indicate a need for doctors to improve their communication skills and for patients to be more involved in the interaction (Jensen, 1981; Onel et al, 1998). This finding suggests that psychosocial concerns are very important to cancer patients, and providing emotional support may help patients adjust more effectively to their disease.

Mackillop et al (1988) compared the perceptions of one hundred patients with the views of clinicians, regarding the probability of cure. They found that patients were more optimistic than the clinicians, which suggests that either patients were interpreting the information in a more positive light, or that physicians were communicating the information in a way that gave the impression that cure was more likely. Further, in a subset of forty-eight patients who were being treated palliatively, most believed that treatment would prolong their lives, contrary to the responses given by the clinicians. In this study the interviewer was unaware of the specific diagnosis of each patient, and therefore, could not tailor the questions to the individual circumstances of the interviewees. Thus, the findings could be problematic since the individual circumstances of each patient could have affected the responses that were obtained.

Reynolds et al (1981) have shown that the way in which information is presented to patients influences both their recall and understanding. Also, the cancer patients in a study carried out by Buchanan et al (1996) felt that cancer pain was untreatable and as a result they were more likely to refuse certain drugs. However, this view differed from that of the oncologists in the hospital from where the patients were recruited for the study. Other studies have shown that when

compared to the general population, former cancer patients who have completed their treatment tend to view their life expectancy less optimistically. This suggests that cancer patients adjust to their illness, and begin to view their illness and prognosis more in line with the biomedical model (Van der Donk et al, 1995).

Incongruent frames of reference between doctors and patients have often been held responsible for communication difficulties (Goffmann, 1968; Mathews, 1983; Buchanan et al, 1996). As a result, the specialised nature of medical knowledge sometimes prevents patients from successfully negotiating their interests. For instance, Blanchard et al, (1990) showed in their study of doctor-patient communication, that doctors often continue talking without paying attention to the patient's input. Selective topics are chosen for discussion to avoid sensitive issues, and technical words and euphemisms are often adopted to maintain a 'professional' distance with the patient. Non-verbal cues may include walking away from the patient without giving an answer to a question and limiting the time available for a consultation. However, these findings should be treated with caution as they may not be generalisable to different clinical settings. Freidson (1970) similarly argued that doctors often control the communication process by withholding information from patients, and by revealing it slowly, one stage at a time. Quine and Rutter (1994) interviewed one hundred and sixty six mothers of children with severe learning disabilities about how they were told the diagnosis. Usually, one parent was told the diagnosis alone and left to inform the other. However, parents found this unsatisfactory, and preferred to be told at the same time.

Summary

The research evidence in this section shows that there are profound communication difficulties between doctors and patients. These problems seem to be intensified between specialists and cancer patients whose illness may have a disabling effect on their ability to participate in the interaction with their doctor. Although many of the studies reviewed above focused on different communication issues, it is evident that most significant on the list are those which relate to the use of technical language by the doctor. The conflicting frames of reference used by doctors and patients often make it difficult to reconcile the needs of patients and the concerns of the clinician. Many of the studies investigating the communication process have also tended to focus on the views of patients and doctors in isolation of each other, and questionnaire or survey based studies have mostly been used for this purpose. There is a need to carry out further research on the doctor-patient communication process, using qualitative and observation designs in order to identify in more detail the communication barriers that exist in the cancer consultation. Although

many studies have identified differences between doctors and patients in their understanding of the clinical problem, very few have explained the underlying reasons for these differences. In addition, since the cancer consultation usually occurs on several different occasions, future investigations should concentrate more on the changing nature of the doctor-patient relationship and the changing information needs of cancer patients. Hopefully, this approach will identify some of the common communication problems that take place within the consultation.

Information disclosure in cancer care

The attitudes of physicians and cultural variations regarding truth disclosure

As discussed above, the communication process in cancer therapy can be problematic. Consequently, the specialist must decide not only how to disclose the information to patients but what he or she feels counts as the 'truth' (Jolley, 1988; Deber, 1994; Buckman, 1996).

The communication of bad news can have a profound effect on the clinician, who may feel uncomfortable using words such as cancer, and may prefer to adopt euphemisms such as 'tumour', 'growth' or 'cyst', in order to minimise any distress during the consultation (Meredith et al, 1996). In a landmark study conducted in 1961, 90% of a sample of 219 clinicians in the USA reported that they would not tell a patient that they had cancer (Oken, 1961). Almost twenty years later a similar study conducted on 264 physicians found that 97% would disclose a diagnosis of cancer to a patient (Novack et al, 1979). This dramatic shift demonstrates the changing attitudes of physicians in the USA towards the disclosure of truth to cancer patients. The changing attitude has partly been influenced by the growing public demand to be fully informed, the increase in litigation against doctors, and the medical profession's desire to maintain the patient's trust (Hebert et al, 1997). Indeed, the disclosure of truth can have a positive effect on health outcomes, both physical and psychological (Henbest and Stewart, 1990), as well as help to improve patient compliance (Eraker et al, 1984).

One study found that physicians can control the flow of information to patients and thereby help to reinforce an unequal balance of power in the consultation (Miyaji, 1993). In this study physicians claimed that they wanted to portray themselves as trustworthy, caring, and sincere, through the control of information, and by maintaining the patients' emotional dependence on

their medical skill. In a similar vein, a study carried out by Thomsen et al (1993) on the attitudes of gastroenterologists towards the disclosure of a cancer diagnosis to patients showed that gastroenterologists in southern and eastern Europe adopted a paternalistic communication style whereby they withheld the cancer diagnosis from patients, preferring to inform the spouse instead. Gastroenterologists in northern Europe however, were more intent on preserving the patient's right to know, by informing patients of their diagnosis. These two studies suggest that doctors still retain the power, not only to decide how to inform patients, but whether to inform them at all.

In another study, Mitsuya (1997) investigated the disclosure of truth to cancer sufferers and patients with HIV infection in Japan. There is a persistent belief in Japan that the disclosure of a cancer diagnosis leads to a loss of hope and emotional anxiety in patients, which is why doctors usually disclose such information only to close relatives. This explains why as much as 67% of family members in this study were satisfied that the cancer diagnosis was not imparted to relatives. The fact that HIV status was not disclosed to patients raises important ethical issues, since individuals with HIV may not benefit from potentially life-saving anti-viral therapy. Also, they may unknowingly transmit their infection to others.

A similar study conducted by Elwyn et al (1998) on 77 hospital physicians experienced in treating cancer patients in Japan, explored their views about disclosing the cancer diagnosis to patients. The study revealed that clinicians were highly selective in disclosing the cancer diagnosis to patients. However, all reported that they did inform the relatives. Indeed, some clinicians reported the need to avoid potential conflicts with family members over the disclosure of a cancer diagnosis by respecting the preferences of relatives. Thus, the relatively high degree of non-disclosure among Japanese clinicians can partially be accounted for by their need to respect the expectations and preferences of family members. The study further found that physicians were most likely to disclose the diagnosis to middle-aged patients, and were less likely to tell young or elderly patients. Moreover, there was a tendency to disclose information to patients who had a better prognosis.

Another study carried out in Spain on a sample of sixty doctors' attitudes towards the disclosure of the cancer diagnosis, representing sixteen different specialities, found that only 30% of clinicians informed patients of a cancer diagnosis (Rodriguez-Marin et al, 1996). The study revealed that 55% of doctors only informed patients occasionally, and 15% answered that they never disclosed a cancer diagnosis to patients. Results showed that perceived intelligence and emotional control in patients were the best predictors of the decision by doctors to give information. There were no formal guidelines that dictated the circumstances in which the cancer diagnosis should be communicated, and the majority of doctors (57%) indicated that the policy on disclosure that they adopted was mainly based on their clinical experience.

Also, Boreham and Gibson (1978) note from their study of private medical consultations in Australia, that doctors disclosed a minimal explanation of a diagnosis to less than half the patients, and rarely informed the patients of the causes and the likely course of their illness. A significant finding, given that most patients expressed a need to be informed about their illness. However, the study does not state whether patients were previously informed of their diagnosis by a different specialist, and thus these findings should be treated with caution. Other studies have shown that clinicians only informed patients of their diagnosis if their condition was benign and curable, and they withheld 'bad' news from those patients who they thought would not be able to cope with it (McIntosh, 1976).

Summary

The research evidence presented in this section indicates that although hospital specialists in the UK and the USA are more likely than before to disclose the diagnosis of cancer to patients, there are still large inter-country differences in the way a diagnosis of cancer is communicated. However, much of the research evidence does not provide a clear reason why there are such differences. The different practice styles of clinicians, as well as cultural factors, are likely to account for some of the variation. The evidence here shows that a significant degree of concealment is practised by doctors in Japan towards disclosing the cancer diagnosis to patients, in the belief that such news could lead to emotional distress and a loss of hope. The studies also emphasise the importance of 'cultural' factors and their effect on information disclosure.

Patients' information needs

The traditional view among doctors that patients with a life threatening illness do not want to be told the truth, or that certain information can be 'harmful' to patients, is not supported by the research evidence. One study by Cassileth et al (1980) of cancer patients' information preferences concluded that most patients, irrespective of age, wanted all the possible information that was available. Also, they wanted information regardless of whether it was good or bad news. The patients in this study all had metastatic cancer, and many would have already undergone treatment. It is therefore, important to interpret the findings with caution since the views of these patients may differ from newly diagnosed patients. Certainly, there is evidence that full information (Fallowfield, 1993; Burish and Redd, 1994) and reassurance from the doctor (Sardell

and Trierweiler, 1993), helps cancer patients to maintain hope and adjust more effectively to their illness. Other studies investigating the information and participation preferences of cancer patients, similarly found that patients wanted the most information that was available (Strull et al, 1984; Blanchard et al, 1988; Deber, 1994; Hack et al, 1994; Dunsmore and Quine, 1995; Fallowfield et al, 1995; Luker et al, 1996; Meredith et al, 1996; Graydon et al, 1997).

Elwyn et al (1998) have argued that while universal disclosure promotes the patient's *right* to know the diagnosis, it also confers upon them the *obligation* to know, which essentially substitutes one type of paternalism for another. Thus, the expectation that all patients should be given a certain amount of information could generate difficulties, especially with those individuals who do not wish to know, or who prefer to abdicate responsibility for their care to the clinician. Some patients may need to be taken care of by powerful figures (Lupton et al, 1991). Reynolds et al (1981) found in their study that although many patients preferred to be well informed, this did not necessarily mean that all patients wanted to be told all the information. However, this study included patients with various diagnoses of cancer and with different disease stages, so it is not surprising that some patients did not want to be told all the information.

Some patients want information in order to foster greater participation and to overcome anxiety, other patients prefer to cope with their illness through denial, avoidance and detachment. Contrary to popular belief, the avoidance of information can sometimes preserve hope and optimism (Hinds et al, 1995). For instance, learning that one's prognosis is poor can create feelings of hopelessness and despair. One study investigated the information preferences of 65 cancer patients and found that 87% of European-Americans, 88% of African-Americans, 65% of Mexican-Americans, and 47% of Korean-Americans wanted to be told a diagnosis of metastatic cancer (Blackhall et al, 1995). The authors conclude that it is therefore, important to respect the patient's right not to receive information if they so desire.

Although patients often report a strong desire for information from their doctors, this desire does not necessarily translate itself into information seeking behaviour by the patient. Therefore, the findings from the above studies should be viewed with a degree of caution. However, it should also be noted that information seeking behaviour can also be affected by social class, age, gender, ethnicity and sexuality, as well as a desire to know. Future studies should pay closer attention to the distinction between desire for information and actual information seeking behaviour. Therefore, there is a greater need for observational studies of the doctor-patient encounter.

According to one study, the failure to seek information from doctors was thought to be related to the chronic nature of the illness, which prevented patients from asking questions and engaging in the interaction (Beisecker and Beisecker, 1990). Many of the patients in this study were suffering with debilitating conditions such as muscular dystrophy, chronic back pain, severe arthritis, head trauma, and muscle diseases. A socio-demographic questionnaire was administered

immediately before the interaction, as well as a tape recording of the entire consultation. Also, a tape recording of a subsequent interview with each patient immediately following the consultation was carried out, and an opinion survey was mailed to each informant shortly after the interview.

Manfredi et al (1993), in their study of patient use of treatment related information received from a cancer information service, found that 25% of patients contacting this service requested information about experimental treatment and referrals to cancer specialists, indicating that the patients did not ask their physicians for this information. It appears therefore, that many patients may feel uncomfortable seeking certain types of information from their doctors.

In some cases patients with cancer or a chronic illness may require information on a continuous basis in order to help them adjust to their changing health status. One study of cancer patients who were receiving radiotherapy treatment, reported that some health care providers communicated information inadequately, and were perceived to be inaccessible to patients (Hinds et al, 1995). Some patients felt that the continuity of information was unsatisfactory. Given the small sample size of this study and a lack of a definition for the term 'information' which may have affected its reliability and generalisability, the findings should be treated with caution. The patients were allowed to form their own definition of what was meant by 'information', and therefore, their responses reflected their unique information needs at the time of the interview. Their information needs may have been influenced by their stage in the treatment process and personal circumstances. Indeed, cancer patients are likely to experience change in their health status, and therefore, may require different types of information as their disease advances (Vanwersch et al, 1997).

Summary

Only a few studies have indicated the nature of the information that cancer patients want, and therefore, there is a need for further research in this area. One study found that for one group of cancer patients, the discussion of treatment alternatives was not a top priority at their first meeting with the specialist. However, receiving information about their chances of cure and spread of disease was more important (Degner et al, 1997). A finding which was replicated by Luker et al (1996) and Graydon et al (1997), who found that breast cancer patients were more concerned about survival issues at diagnosis and about the possibility of recurrence. This indicates that information needs may change at different stages of the disease and treatment process. Also,

information needs seem to vary according to various socio-cultural factors, an issue which warrants further investigation.

The influence of family presence in the consultation

There is a growing recognition that the patient's family should become more involved in the management of the patient's illness (Doherty and Baird, 1987; Epstein et al, 1993). Interactions between cancer patients and their oncologists have been studied during regularly scheduled outpatient visits (Labrecque et al, 1991). This study found that the physician provided more information when a family member was present in the consultation, but less emotional assistance was given since doctors assumed that adequate support was available. Similarly, family members asked questions and sought more information, and the physician spent three additional minutes in the consultation if family members were present. The study lends support to the view that patients should be accompanied by relatives at consultations, since oncologists are then likely to disclose more information. Relatives may subsequently be able to provide better advice and support to patients if they have a better understanding of the illness and treatment (Benson and Britten, 1996). Other studies have also reported that the patient with chronic illness who has a 'representative' may be more likely to challenge the doctor and ask for information (McIntosh, 1976).

A study by Marvel et al (1994) however, showed that family presence in the consultation may have a limited impact on the patient's involvement. Most consultations tended to focus on clinically orientated information, and a collaborative dialogue about the views of family members rarely occurred. This indicates that although family presence increases the volume of information which patients are likely to receive, the degree to which doctors are able to become involved with patients and their families is not greatly improved. However, further research investigating the impact of family presence on doctor-patient communication is required, as only a few studies have been conducted to date.

Part III: Decision-making

Defining 'decision-making'

Many investigations seek to study the strategies which patients adopt to decide between different treatment alternatives (Ward et al, 1989), without paying enough attention to how patients decide on a single treatment option. As a result, only the decisions of those who have already agreed to accept a course of treatment are usually investigated. For instance, in cases where breast cancer patients are asked to make a choice between mastectomy and breast conservation therapy, the reasons why patients agree to accept treatment in the first place are frequently left unexplored. Although, some studies have clearly tried to examine this, more research is necessary (Charles et al, 1998).

The definition of treatment 'decision-making' has often been used implicitly in studies, which in turn makes the task of methodological cross-comparison problematic. Some authors have tended to confuse patient involvement in decision-making and patient involvement in the doctor-patient interaction, which has sometimes led to contradictory results between different studies. A few investigations have made a distinction between 'decision-making' and 'problem solving'. The former involves the patient simply deciding on the best treatment option. The latter is a technical task usually conducted by the doctor, which involves assessing the pro's and con's of the different treatment alternatives (Deber, 1994; Deber et al, 1996). Thus, according to Deber (1994) 'decision-making' and 'problem-solving' are defined as two distinctly different operations requiring different cognitive processes. For Deber, patients often take part in 'decision-making', but not in the more complex task of technical 'problem-solving'.

However, it can sometimes be misleading to treat the two concepts separately, since patients often take part in 'problem-solving' tasks even when they do not possess as much technical knowledge as the clinician. Conversely, patients who are seriously ill may be less inclined to play a part in what Deber calls 'decision-making' because of their need to trust the physician during a particularly distressing episode in their lives (Sargeant, 1995). It could be argued that 'problem-solving' is an inherent part of the 'decision-making' task rather than a separate activity. It is also important to stress that decision-making is not simply carried out by either the patient or the doctor. Decision-making is usually a multi-level process, which involves the input of the doctor, the patient, and often the patient's family. Although patients may not appear to be highly involved in the decision-making process during the consultation, they often debate and review the information, which they have been given extensively with their family and friends. Much of the literature however, has concentrated on decision-making within the confines of the clinical

setting. Thus, future research on the treatment decision-making process should define clearly which aspect of decision-making it is investigating.

As Charles et al (1997) demonstrate in their review, the definition of what constitutes decision-making has undergone a marked change in recent years. The boundaries of "informed consent", which are legally enforced as a patient right, are being extended to incorporate the principle of "informed choice", through which the disclosure of treatment alternatives is endorsed. Patients are not only being asked to consent to treatment, but to increase their participation in the doctor-patient encounter by helping to select their therapy (Llewellyn-Thomas et al, 1992). The complex and lengthy process of cancer treatment is usually what distinguishes it from other conditions. Cancer therapy often involves two or more different treatment options, which could have different outcomes, and generate a large amount of uncertainty for the patient. In addition, there is often no right or wrong answer to any decision-making dilemma, and the psychological consequences of each treatment option mean that the need to involve the patient in the problem solving task is becoming increasingly important (Levine et al, 1992; Pierce, 1993).

As a response to the paternalistic decision-making model, it is increasingly recognised that patient involvement in decision-making should be the goal of all doctor-patient interactions. However, neither the medical profession nor researchers investigating treatment decision-making have reached a consensus about what decision-making should involve, or how patient participation in decision-making should be defined. Further, it has only just recently become explicitly more apparent in the literature that information sharing and decision-making are two separate goals in the medical encounter (Fallowfield et al, 1995; Ong et al, 1995). Just because patients express a desire for information or more involvement in the decision-making task, does not mean that they will act in accordance with those preferences. Thus, involvement in the consultation could mean any number of things for different patients. Certainly, important questions still need to be answered. In particular, what do (cancer) patients mean when they express a desire to participate in decision-making.

The model of 'informed' decision-making has been proposed as one that will enable patients to engage more effectively in the task of reaching the most appropriate treatment decision. However, many studies have reported that the benefit of more information does not necessarily equip patients with the means of taking part in decision-making. Instead, information often only provides them with emotional and psychological reassurance (Fallowfield, 1997). Further, Charles et al (1997) contend that the test of a shared decision, is if both the doctor and the patient agree on the treatment option. This does not mean though, that both parties totally agree that the agreed option is the best one, but rather they both endorse it as the most acceptable treatment to implement. Thus, mutual acceptance is an important characteristic, which distinguishes shared decision-making from both the more unequal paternalistic and informed models.

A further complicating factor in the search for a better definition of what constitutes shared decision-making, is that many consultations may start by representing one model of interaction but evolve into another model as the encounter unfolds. The shared decision-making model has been advocated as the optimal way through which the best choices can be reached. However, the research evidence indicates that patients with serious illnesses prefer to delegate the treatment decision-making task to the clinician (Degner and Sloan, 1992; Beisecker et al, 1994; Fallowfield 1997). Coulter (1997) in her review of the decision-making literature supports the claim that often patients do not want a shared decision-making role. In fact, a shared decision-making approach can be very difficult to achieve, because clinical information may cause additional distress to patients.

In addition, Coulter (1997) suggests that it might be too costly, too difficult, time consuming, and impractical to provide patients with complete information. Some patients may be more able to communicate their preference than others and demand more intervention, which could lead to greater inequity in access to treatment. As Coulter (1997) indicates, there are real tensions involved in encouraging individual demands while maintaining overall benefits to the whole population. However, she does state that a more educated patient population does have some advantages. For instance, there is some evidence to suggest that women with higher education are much less likely to agree to hysterectomy than women without formal qualifications. Thus, well informed individuals may resist medical intervention when the need for it is perceived to be questionable (Coulter, 1991; Coulter et al, 1994).

In summary, the literature only provides a partial answer to the question of how far patients participate in treatment decision-making, since much of the research conducted to date has neglected the reciprocal nature of the interaction, the definition of what involves 'decision-making', and also the role of the physician (Charles et al, 1997).

The importance of decision-analysis

The definition of 'decision-making' has in part been shaped by health economists in their endeavour to demonstrate the contribution that 'decision-analysis' can make to health care. Maynard (1997) argues that scientific evidence of clinical 'effectiveness' should not be the primary means of arriving at treatment decisions, since clinicians will be compelled to select the most effective rather than the most 'efficient' options. Hence, those which are the best for the individual patient rather than society (Moss and Cronau, 1995). Rationalist decision-making has

been criticised by those who believe that conflicting values exist in every society, which cannot always be resolved through clear-cut solutions (Klein et al, 1996). As Isaiah Berlin proclaimed;

To suppose that we can escape this conflict of values by retreating to an ideologically and organisationally simpler world casts a veil of deceit over the choices that must be made (cited in Weale, 1998).

Brock and Wartman's (1990) gold standard of rational decision-making, the 'expected utility theory', suggests that patients often do not make rational decisions as their choices are coloured by their subjectivity. Such assertions have been challenged for assuming that if patient choices deviate from the scientific model then they must be irrational. Many people make choices which may seem irrational from a scientific point of view, but in the light of their values the choices can also seem very rational (Barr, 1990; Gafni, 1990). Often people do not have well-defined preferences, and the choices which are made are often less than optimal, and at times inconsistent, with the stated values of the decision-maker (Elstein, 1976; Eraker and Politser, 1982; Barr, 1990). In short, decision-analysis tends to over-simplify the strategies inherent in decision-making by treating the data 'neutrally', and by dismissing any ambiguity surrounding the decision-making dilemma (Eraker and Polister, 1982).

Silverman (1995) raised the distinction between 'reasonable' versus 'rational' choice, in which the former is achieved through a system of co-operation between doctor and patient, and the latter is a search for the most effective means to an end. Indeed, the author concludes that there are certain things that one party cannot do to another without his/her consent, despite the costs and benefits.

Pauker and Kassirer (1980, 1987) claim that when two different approaches to managing a patient appear to have the same potential value, the decision faced by the physician is often described as a 'toss-up'. In their view, a decision-analytic approach enables the clinician to make a more rational judgement regarding the most appropriate therapy, in circumstances where a reasoned decision cannot be made (Hazen et al, 1991; Verhoef et al, 1991; Smith and Bodurtha, 1995; Robinson and Balducci, 1995). For instance, in the management of early stage prostate cancer, radical surgery has the same survival outcome as a 'wait and watch' policy (Chadwick et al, 1991). Decisions on the best way to treat cancer patients are notoriously difficult, one reason is that treatments carry a considerable degree of risk and uncertainty. However, proponents of rationalist decision-making have argued that even though a systematic approach to decision-making has some pitfalls, it nevertheless can help to convert the complexities of cancer management into a more simplified and quantifiable process (Henschke and Flehinger, 1967; Eraker and Polister, 1982; Beck and Scardino, 1994; Dowie, 1998).

The extent of patient participation in treatment decision-making

Much of the research, which has been conducted in recent years on treatment decision-making, has sought to assess how far patients participate in this task. Many of the results often point towards different conclusions. However, the overall message suggests that cancer patients do not frequently desire to play an active part in decision-making, instead preferring to allow the physician to assume most responsibility. It is the literature connected to this question which is reviewed in this section.

According to Freedman's (1974) moral theory of informed consent, a central component in decision-making is the 'capability' of a patient to reach a valid decision. The patient needs to show capability in comprehending the legal, social and medical implications of the decision that he or she is making. Their capability is a necessary condition for making a valid decision. Freedman claims that:

A patient's "capability" is judged to be dubious when he or she is unable to reach a decision that, given the same or similar circumstances, would have been reached by any reasonable person (1974).

However, in cancer therapy what seems to be a reasonable decision for one individual may be completely unreasonable for another. Thus, the idea of a 'reasonable' decision often cannot justifiably be applied in cancer care. Decision-making in cancer can be a subjective process along which the clinician can only guide the patient. As a result, there has been a trend in the literature to investigate how far cancer patients want to take part in the decision-making task. Some researchers have made the assumption that cancer patients should be involved in selecting their own treatment (Dunsmore and Quine, 1995), following the consumerist ethos that it is in the patient's interest to participate in decision-making, since greater participation correlates positively with better psychological adjustment (Haigh, 1993; Schapira et al, 1997).

The evidence supporting patient participation in decision-making

Often the treatment choices which individuals suffering with a life threatening illness make can be radically different to those of people without such an illness. One of the reasons why some studies have indicated that people prefer greater involvement in decision-making, is because much of the research has been conducted using hypothetical scenarios and with people without a cancer diagnosis.

The results of two important studies conducted in the 1980s by Cassileth et al (1980) and Blanchard et al (1988), show that patients with cancer sometimes want active involvement in the decision-making process. Both studies used a two-item indicator of role preferences (rather than the more detailed five-item indicator used by Beaver et al, 1996, and Degner and Sloan, 1992, and found that two thirds of cancer patients expressed a preference to participate in treatment decision-making. One of the reasons for this could be that the two item indicators used by Cassileth et al (1980) and Blanchard et al, only reflected the two options that they were given: either participation or non-participation in decision-making. As a result, these responses may have been less accurate than the five item-indicators used by Beaver et al (1996) (please refer to the next section). Another study of patients with various cancer diagnoses found that patients wanted to be involved in the decision-making task, and wanted to feel that they had pursued all their options before making a decision (Manfredi et al, 1993). However, this study only reported how far patients and their relatives would want to be involved in decision-making, rather than the degree to which they did in fact participate in decision-making. Patients with longstanding illnesses were excluded from the study, which means that only those with recent diagnoses took part. This could drastically affect the types of responses that were obtained, as could the fact that 44% of the sample were not actual cancer patients but relatives.

Lewis et al (1997) carried out a qualitative study on the decision-making practices of older patients with cancer. The respondents were six Cancer Centre Nurse Co-ordinators (CCNC's) who conducted telephone conversations with older cancer patients over a sixteen-week period. In addition, most patients were at least six months' post diagnosis. The study concluded that patients played an active part in discussing decisions with the nurse co-ordinators. The reasons for the phone calls varied in scope, from immediate issues such as what to do for a high temperature, to more long term concerns regarding what arrangements to make for a spouse with Alzheimer's disease once the patient had died. Many patients also sought reassurance from a nurse to remove any doubt that they had made the best decision. However, the drawback of the study was that all the callers were a selective group, since they made a conscious decision to phone for health care

advice. Also, the fact that interviews were conducted by telephone rather than face-to-face raises further issues about the credibility of the data. Nevertheless, the study does support the view that in time, patients do seek further advice and a continuity of information, as reported by Hinds et al (1995). Thus, the crucial factor which affected cancer patients' desire to become involved in treatment decision-making may not be disease severity as such, but time.

Offering treatment, especially chemotherapy drugs, as part of clinical trials is becoming widely regarded as the best way to provide additional or 'adjuvant' treatment to cancer patients. As a result, patients are often faced with the need to decide whether they want to delegate the decision-making task to a process of 'randomisation', rather than choose the treatment themselves. Thus, the nature of decision-making is changing, at least in oncology. One study of patients with colorectal cancer reported that those who refused entry into a trial (25 patients agreed to trial entry and 35 refused) did so because they objected to the randomisation process, and because they demanded greater participation in decision-making (Llewellyn-Thomas et al, 1991). The same five-item questionnaire was used as that developed by Cassileth et al (1980), where patients were presented with five descriptive sentences ranging from preferring that the doctor assume primary responsibility for decision-making, to preferring that the patient do so. The study adds to the body of evidence that some cancer patients prefer greater control over the decision-making task. However, the questionnaire was administered retrospectively to patients with both early and metastatic cancer. Therefore, caution should be exercised in interpreting these findings since there is evidence that patients who have advanced disease, have different views about decision-making, than those with early or benign disease (Beaver et al, 1996). Also, newly diagnosed patients hold different views to those who have had time to adjust to their illness.

A recent study which investigated palliative cancer patients' preferences for involvement in treatment decision-making, found that most (80%) patients wanted a collaborative role in decision-making and some wanted sole responsibility (Rothenbacher et al, 1997). Also, the patients with advanced ovarian cancer in Elit et al's (1996) study, wanted to be fully informed and take part in deciding on their treatment. However, the treatment aims available to terminally ill patients are very different to those presented to patients with 'curable' cancer, and therefore, the findings may only be generalisable to patients with advanced disease. When cure is possible, patients may require the specialist's expertise to advise on the most effective treatment, but when cure is no longer a realistic option, patients may prefer greater control over the management of their illness. Certainly, patients with advanced disease may have had more time in which to assess their condition and plan the type of management they would prefer if their disease progressed.

Hack et al (1994) conducted a study on breast cancer patients' information needs and decision-making preferences, and found that those patients who wanted more information also wanted to play a greater part in treatment decision-making. All the patients had early stage disease. However, only half of the patients who wanted a passive role in decision-making, also wanted to

be well informed by the doctor. This study supports the view that breast cancer patients who want information, also want to be involved in decision-making. The authors suggested that it is possible that patients who have adapted to their illness are more likely to seek more information and become involved in decision-making. Thus, the patients in this study who wanted greater participation, could have been more adjusted to their illness. Indeed, the patients in this study were interviewed between two and six months' post-diagnosis, which could have been enough time in which to adjust to the disease. However, given the small sample size (35 breast cancer patients) it may be questionable whether women in this study were representative with respect to the wider population of patients with stage I and II breast cancer.

Summary

The research reviewed in this section indicates that although some patients with cancer claim they want to play a more active role in choosing their treatment, most of the above studies have failed to provide a definition of 'decision-making', and what is meant by 'greater' participation. As a result, the conclusions that are drawn from these studies need to be interpreted with caution since the absence of an accepted definition of 'decision-making', and the use of different study designs, make comparability difficult. The above studies only provide a partial answer to whether cancer patients participate more in decision-making for another reason. Much of the research has been conducted with breast cancer patients around surgical treatment options. For this reason, mainly the views of breast cancer patients regarding their choice of surgical treatment have been investigated. Therefore, future studies need to be conducted on the views of patients with different cancers, as well as their treatment preferences regarding chemotherapy and radiotherapy.

In addition, these studies have generally investigated patients' responses to hypothetical scenarios. However, there is a serious absence of observational studies that provide empirical data of how patients with cancer participate in the decision-making process.

The evidence against patient participation in decision-making

Being freed from the responsibility for decision-making may produce a sense of relief, as the responsibility for the outcome of the decision is transferred to the doctor. Certainly, what patients may really want is information rather than involvement in treatment decision-making (Sutherland et al, 1989; Beisecker et al, 1994; Marteau, 1995; Fallowfield 1997). Beisecker et al (1994) suggest that consumerist groups advocate patient involvement in decision-making. However, there is mounting evidence which increasingly shows that cancer patients do not want a large part in making treatment decisions. Thus, the key to the autonomy issue could be situated in patients' need for information, rather than treatment choice. Beaver et al (1996) for instance, conducted a well designed study comparing treatment decision-making preferences of women newly diagnosed with breast cancer, and a comparison group of women diagnosed with benign disease. A card sort technique was used, where five cards were shown to patients describing the potential role that could be played in treatment decision-making. The roles ranged from active through to collaborative and finally passive. The results showed that the majority of women newly diagnosed with breast cancer preferred to leave treatment decision-making to the doctor. The benign group however, overwhelmingly preferred to play an active role in decision-making. The results suggest that a cancer diagnosis had a disabling effect on the desire to participate in decision-making. It could be that decision-making ability was limited due to the life threatening nature of the disease.

Degner and Sloan (1992) conducted a large study using the same card sort technique, comparing 436 newly diagnosed breast cancer patients with 482 members of the general public. They also found that a high proportion of cancer patients wanted to delegate treatment decision-making to the doctor, whereas the comparison group preferred to play a more 'active' part in decision-making. Thus, the presence or absence of disease appeared to play a central role in people's desire to participate in decision-making.

Fallowfield et al (1994) support the view that breast cancer patients often want to be well informed but do not necessarily want to participate in decision-making. The closer that people get to being 'real' patients, the more guidance they may require regarding decision-making (Degner and Sloan, 1992; Fallowfield, 1997). Indeed, the authors claim that it is the right of patients not only to receive information from their doctor but to decline decision-making responsibility and nominate the clinician for this task. The women in Fallowfield et al's study clearly felt that they did not have enough expertise to make treatment decisions without the clinician's guidance. Indeed, another study found that as patients' illnesses worsen, they demand less involvement in

decision-making (Butow et al, 1997). It is also important to understand that non-participation for some patients is in itself a form of participation, whereby patients may actively decide not to participate in decision-making as a means of helping them adapt to their illness. Similarly, patients may prefer more information, but this does not always mean that they want to play a more active part in treatment decision-making (Hack et al, 1994).

A qualitative study conducted by Meredith (1993) on patients in surgical wards found that specialist-patient encounters were not conducive to facilitating patient participation in the decision-making process nor to them obtaining adequate information. The study indicated that patients wanted greater involvement in the doctor-patient encounter. However, it is unclear from the study if patients preferred more information, or if they wanted to make the treatment decision. Although many patients indicated that they wanted to participate in the interaction, this does not necessarily mean that they also wanted to make the treatment decision. The data is therefore, somewhat unclear.

Further, in a study investigating decision-making preferences of patients with hypertension, Strull et al (1984) found that patients wanted their doctor to provide them with extensive information. However, in actual decision-making patients reported playing a relatively passive role, leaving the decision-making task to the clinician in 63% of cases. In addition, only 53% of patients expressed a desire to participate in such decisions. The study also found that clinicians tended to over estimate patients' desire to participate in decision-making and underestimate their need for information. The study further supports the theory that patients with a chronic illness may prefer to play a more limited part in treatment decision-making, since the severity of their illness may preclude them from assuming responsibility for this task. In this study 210 patients and 50 clinicians in three different settings were interviewed using a structured questionnaire about their decision-making preferences. Thus, the generalisability of the findings is strengthened.

Sutherland et al (1989) reported in their study of decision-making preferences of cancer patients with various malignancies, that 63% wanted a passive role in decision-making. However, caution should be exercised over the generalisability of the findings since the study subjects were recruited as a convenience sample and the sample size was limited (52). Also, two thirds of the participants in the study were female, and male patients who were not recruited into the study may have had different views about decision-making than the actual study participants. Similar conclusions were reached by Pierce's (1993) study, where women with breast cancer regardless of age, found that the physician's recommendation had the greatest influence on their choice of treatment. Younger women however, were more likely to seek information and participate in decision-making as assurance that they were receiving appropriate treatment. This study employed open-ended interviews with 48 women who had early breast cancer and were in the process of making a treatment decision (lumpectomy versus mastectomy). Although the doctor's

recommendation had the greatest influence on patients' treatment choice, the study does not explain what that recommendation might have been, or what kind of a role the clinician played in the decision-making task. However, the findings in this study were very insightful and complement the findings of other qualitative investigations (Charles et al, 1998).

Ward et al (1989), in their study investigating patient preferences of breast conservation surgery or modified radical mastectomy, found that patients preferred a collaborative decision-making style. No one in the study wanted to abdicate decision-making to the doctor. However, several patients claimed that they would have preferred it if the clinician had expressed a preference for a certain course of action, in order to help them with their decision. This suggests that patients wanted the decision-making task to be a joint effort between them and the doctor. The findings in this study are highly significant since they illustrate the complex nature of decision-making, and the fact that the role of the patient cannot be simply dichotomised as 'active' or 'passive'. Investigating the interactive nature of the doctor-patient encounter is central to understanding the decision-making process. However, since only a total of 22 women participated in the study, the extent to which the findings are generalisable is called into question.

The findings are similar to those of a study conducted by Johnson et al (1996) on women with early stage breast cancer. Although patients claimed they wanted to be well informed, 74% claimed that they also wanted the doctor to provide a recommendation, which they followed 93.8% of the time. This figure is in agreement with the finding of Degner and Sloan (1992), where 59% of newly diagnosed cancer patients wanted their physicians to make a treatment decision. Buchanan et al (1996) and Ashcroft et al (1985) also found that cancer patients preferred a joint decision-making style. Johnson et al, (1996) reported that younger women under the age of 40 were more likely to demand a physician's treatment recommendation, which challenges the notion that younger health care consumers want to make treatment decisions independently. However, more exploratory studies are still required to determine more specifically the degree to which cancer patients want to avoid decision-making responsibility.

Similarly, Degner et al (1997) found in their study of breast cancer patients that most wanted either to accept sole responsibility for decision-making or to make a joint decision. The most striking finding from the study, however, was that many patients were not satisfied with the level of their participation in decision-making. Women who wanted a passive role in decision-making felt that they had been 'pushed' into a more passive role than they desired. This could be related to a feeling on the part of women that they did not really have much choice now that they were facing a life threatening condition. This finding is supported by Charles et al (1998) and Siminoff et al (1989). Moreover, Siminoff et al (1989) reported in an analysis of interactions between women with breast cancer and their physicians, that most patients were reactive rather than proactive.

The cancer patients in Tabak's (1995) study were terminally ill, and therefore, subject to feeling that time was too short for gathering information and reaching a reasoned decision. The author refers to this behaviour as 'defensive avoidance', where the patient abdicates responsibility for decision-making to the clinician. This finding is supported by other similar studies (England and Evans, 1992; Sensky and Catalan, 1992; Beisecker et al, 1994; Deber et al, 1996; Johnson et al, 1996; Reaby, 1998). Similarly, Meyer et al (1995) found that older breast cancer patients arrived at their decisions more quickly than did younger women, which helped them to reduce the period of uncertainty and avoid the cognitive overload involved in reaching a treatment decision. The younger women were better educated than older women, which indicates that a higher degree of education can lead to a delay in deciding about treatment. This study used hypothetical questions and thus the findings only represent patient views rather than real life decisions. However, the study yielded some very interesting insights into the role played by older breast cancer patients in decision-making. Other studies also found that older breast cancer patients tended to defer the decision-making responsibility to the doctor (Pierce, 1993; Street et al, 1995; Deber et al, 1996; Turkcharles et al, 1997).

Summary

The studies in this section largely based their conclusions on the views of patients. However, due to the life threatening nature of cancer most patients preferred to delegate the decision-making responsibility to the doctor, since time was too short in which to make a decision. It was also reported that sometimes the doctor-patient interaction is not always conducive to greater patient involvement in the decision-making process. In many studies, patients actually wanted the clinician to provide a treatment recommendation in order to help them along in the decision-making task. As reported in the previous sections, many studies investigating treatment decision-making have focused on breast cancer, hypothetical scenarios, and the views of non-cancer patients. Therefore, some of the conclusions that are drawn from these studies should be interpreted with caution, especially in the absence of an agreed definition of 'decision-making'. However, a large section of the research evidence indicates that cancer patients certainly do not want to be excluded from the decision-making task, but neither do they want to make treatment decisions in isolation of the clinician. It is strongly evident that although cancer patients may have a treatment preference, they often prefer to discuss the options that are available and consider the doctor's recommendation. Thus, the most sensible conclusion that can be drawn from the existing

studies is that patients want some involvement in the management of their illness, but they may also require an 'expert' to lead them in the 'problem-solving' and the decision-making tasks.

In answer to whether cancer patients prefer to be more involved in decision-making or more informed, the research evidence suggests that the life threatening nature of cancer leads patients to defer responsibility for their management to the clinician. The studies in this section show that patients want to be well informed, but they rarely want to make the final treatment decision without the recommendation of the clinician. The study by Fallowfield et al (1994) provides good evidence that information is often more central to patients' needs than involvement in decision-making. So, although patients may prefer to be included in the decision-making task, this does not mean that they want to make the final decision regarding their management. The above studies also indicate that patient participation in decision-making could be influenced by disease stage. However, the studies investigating patients' preferences around palliative treatment largely report the views of patients who are not facing actual decisions. Much of the evidence is based on patients' views about how much they would like to participate in decision-making, rather than the extent to which they actually participate in practice.

Factors influencing decision-making

In this section, some of the factors that influence treatment decision-making are reviewed. Many studies investigating patients' decision-making preferences assume that cancer patients want to participate in the decision-making process, and do not adequately explore the reasons for their choices. Instead, a large number of investigations focus on the reasons why patients choose a treatment regimen amongst several options. Thus, the implication is that patients want to make treatment choices. As the above section indicates, much of the research shows that cancer patients certainly do not always prefer to make treatment decisions alone. More research therefore needs to be conducted, which investigates the factors that influence people to accept or reject cancer treatment outright, and in particular how patients decide on oncological treatment.

Psychological factors

Cancer patients are often influenced in their choice of treatment by various psychosocial and psychological factors, such as the impact that treatment could have on their domestic circumstances or the degree to which toxic treatment could affect their quality of life. In this section some of the psychological influences on patient decision-making are reviewed.

Wilson et al (1988) reported in their study of women with early breast cancer, that patients preferred to have radical mastectomy over conservative management since they wanted to avert the possibility of having radical surgery in the future. They claimed that conservative management would not reduce their fear of recurrence as effectively as mastectomy. The fear of recurrence was cited as one of the most important reasons why breast cancer patients chose mastectomy in one review on the treatment choices of breast cancer patients (Slevin et al, 1990; Long, 1993).

Fallowfield et al (1990) also carried out a large multicentre study on women with early breast cancer and concluded that breast conserving procedures do not protect women with breast cancer from psychological and sexual dysfunction. Again, the fear of cancer and its potential for recurrence appeared to be a compelling factor in women's treatment preference. Body image was reported to have played a small part in the patients' treatment choices. Patients were recruited from 12 district general hospitals, 3 teaching hospitals, and 4 private hospitals. There was a 90% response rate. Fallowfield et al (1990) warn against attempts to advocate greater patient participation in decision-making. They identify a potential difficulty that patients may subsequently assume responsibility for the outcome of the treatment, and if the outcome is negative they may experience greater psychological distress. Indeed, breast cancer patients have been reported to defer to the doctor's judgement by adopting complacency and defensive avoidance strategies as a way of diverting responsibility for the treatment decision (Reaby, 1998). This observation was also reported by Morris and Ingham (1988), in a study of psychological adjustment following choice of mastectomy versus lumpectomy for early breast cancer.

Another study evaluating an interactive video simulation used as an educational tool intended for patients with breast cancer found that respondents preferred breast-conserving surgery to mastectomy. This was because having a mastectomy straight away left them with no 'back-up' treatment (Chapman et al, 1995). The study subjects however, were all university students with no history of cancer. Therefore, the study only predicted which treatment options individuals would choose in the event that they developed breast cancer. Consequently, the extent to which they can be generalised to patients with an actual diagnosis of breast cancer is suspect.

In one study, 109 patients diagnosed with breast cancer were followed up for one year following surgery to evaluate the impact of radical mastectomy and breast conserving surgery on

psychological adjustment (Ganz et al, 1992). The study found no significant differences in quality of life, mood or psychosocial adjustment between women who had radical surgery or lumpectomy with radiation. It has been reported by other studies that women receiving radical mastectomy experience more psychological distress and problems of adjustment (Ashcroft et al, 1985; Morris and Royle, 1988). However, this study concludes that patients played some role in the decision-making process, which could have helped to buffer them from any potential psychological problems. Ganz et al (1992) also claimed that many other studies investigating decision-making for early breast cancer have tended to emphasise the loss of a breast as the most important event rather than the diagnosis of cancer. This study supports the view that the diagnosis of cancer is a greater predictor of psychological distress than the type of surgery. This was a well designed study as patients were interviewed at three separate time points (3, 6, and 12 months after the initial assessment), at which time they had a full quality of life and a psychological adjustment assessment. Similarly, other studies have shown that when cancer patients are given a treatment choice, even when they decide to follow the surgeon's advice, they tend to experience significantly reduced psychological distress (Morris and Ingham, 1988; Williams 1995).

Schover, (1995) found in a retrospective study of women choosing mastectomy versus breast conservation surgery, that there were no differences in psychological adjustment between the two procedures. The study reported however, a significantly poorer psychological adjustment and impaired body image amongst those women who underwent chemotherapy. At least part of the impact of chemotherapy may be related to women's perceptions that they had a poorer prognosis for disease free survival. This study adds to the growing body of evidence that local therapy (surgery) for early breast cancer is not a crucial factor in psychological adjustment to the disease. However, the questionnaires in this study were mailed by post to 499 women with breast cancer and only 218 replied (47% response rate). Due to the poor response rate of the study the results may have a limited external validity. Also, the informants who replied, were four years post diagnosis on average, and the study does not measure their changing psychological status since their diagnosis. It only measures their psychological status at the time of the study. The sexual function of the women was taken into account. However, other factors that could have been important, such as disease stage and other comorbidities, were not included in the study. As a result the study does not provide entirely satisfactory evidence that the cancer diagnosis is more important than surgery in explaining women's psychological adjustment.

England and Evans (1992) carried out a study on 143 patients in a cardiovascular risk management clinic to assess patient's desire to become involved in treatment decisions. The study found that the degree of control that subjects reported that they had over the final decision varied considerably. Patients reported that their perceived control was positively associated with their prior beliefs about how much control they had over their health in general. Also, having a risky or

a dangerous health state, in this case having high blood pressure, was associated with a lower perceived sense of control over the decision-making process. The study concluded that encouraging patients to participate in decision-making does not guarantee a sense of control in all patients. Margalith and Shapiro (1997) also found in their study that patient participation in clinical decision-making did not contribute to a decline in anxiety among patients who were referred to a urologist for removal of a ureteral stone. On the contrary, when patients did not participate in decision-making, their anxiety levels declined. However, what did correlate positively with lower anxiety, was the patients' perceived involvement in treatment decision-making and their satisfaction with the information, which they were provided. This suggests that the anxiety levels of patients decrease when they perceive that they have been given relevant information, but not necessarily when they have participated in decision-making. Fallowfield (1997) also reported that patients wanted information without the obligation of taking part in the treatment decision-making process, which in-itself could evoke anxiety. These findings add strength to the view that cancer patients do not want to make treatment decisions alone.

Other studies have reported that the duration of hospital stay by patients undergoing surgery for breast cancer has a significant impact on patients' psychological adjustment and morbidity. The vast majority of patients preferred a shorter hospital stay after surgery, and early discharge enhanced their opportunity for better social support within the family (Bonnema et al, 1998). Also, increased attention to patients' information needs at discharge could help to reduce the level of uncertainty and facilitate the transition from hospital to home (Galloway and Graydon, 1996).

Summary

The studies in this section suggest that the anticipated psychosocial impact of certain treatment choices can play a central role in the decision-making task. Much of the psychological research often gives the impression that cancer patients play a greater part in decision-making than they actually do in practice, by focusing largely on patients' views and opinions. More emphasis should be placed on the role of the clinician as well as the patient in decision-making, in order to provide a more balanced picture.

The dominant theme in the psychological research literature indicates that body image is not necessarily the most important factor for breast cancer patients when facing treatment decisions. The studies suggest that breast cancer patients are more concerned with survival issues, and the loss of a breast may often be regarded as a necessary option that can reduce the possibility of death. The research also suggests that there are few differences in the anxiety levels of women

undergoing breast conservation surgery and radical mastectomy. Thus, women often make treatment choices based on their perception of treatment effectiveness rather than body image. Further, the above studies lend support to the view that not all cancer patients want to be responsible for selecting their treatment. Much of the research conducted on the psychosocial impact of treatment choice has concentrated on patients with early stage breast cancer. Thus, more research needs to be carried out to investigate the psychosocial impact of different treatment options on patients with different cancers.

Survival

Another study on the decision-making preferences of patients with advanced ovarian cancer, found that the way in which the information is framed can influence patients' treatment choice (Elit et al, 1996). For instance, the study found that survival information significantly affected treatment choice, and the vast majority of palliative patients (67%) still opted for the treatment which would give them the longest survival benefit, and most toxicity. Patients who are terminally ill with cancer, often report that they wish to continue the 'fight' against their disease even when the chances of success are very low. In one study only 5% of patients terminally ill with gynaecological cancer claimed that they would anticipate giving up the fight against their disease, whereas 77% expressed a resolve to continue the fight (Brown et al, 1994). Similarly, Yates et al (1993) conducted an investigation of the attitudes of terminally ill patients with cancer towards alternative therapies. The study found that patients using alternative therapies in addition to conventional treatment had higher scores on the 'will to live' scale and were less willing to accept the finality of their prognosis. Further, these patients also had a greater desire for control over treatment decisions. The results of this study support those conducted by Downer (1994), suggesting that when patients reach the terminal stage of their illness they demand more control over the management of their illness.

It has also been reported that cancer patients agree to undergo high toxicity chemotherapy for a relatively small increase in survival. McQuellon et al (1995) found in their hypothetical study of early-stage breast cancer patients, that fifteen percent of patients would prefer high risk treatment for as little as one month added life expectancy. The study also found that between 34% and 82% of patients would accept toxic treatment for only a six-month addition to life expectancy, and almost all patients would accept treatment for a five-year increase in survival. Moreover, 76% of patients would accept a toxic chemotherapy agent to reduce pain even if such treatment did not prolong life. These findings support those of Yellen and Cella (1995), where 45% of 296 cancer

patients claimed that they would accept mildly toxic treatment for a mere 1% increase in the chances of cure. Another study by Mazur and Hickman (1996) also found that patients with localised prostate cancer preferred radical surgery over expectant management, since surgery offered the possibility of complete tumour removal. The fear of recurrence often impacts on patients' quality of life to such an extent that they are willing to accept the risks and inconvenience of radical therapy (Hayman et al, 1997).

One issue in oncology, which has not been adequately resolved, relates to whether older cancer patients should be subjected to radical or toxic treatments given the fact that their tolerance level is lower than that of younger patients. The conventional wisdom is that tumours are somewhat less aggressive, but interventions not as well tolerated in older people. However, given that over half of the cases of cancer occur in the over 65 year olds, it is important to conduct further research into whether older patients tolerate cancer treatment less well than younger individuals (Ershler and Balducci, 1994). This is especially important in the case of colorectal cancer where there is an increase in incidence after the age of 65. Indeed, Casey et al (1992) studied 41 men aged 80-92 who underwent radiation therapy for various cancers, and found that they tolerated the treatments without complications. Also, since quality of life becomes a more important issue in older populations, more evidence is needed to inform how a balance can be struck between providing optimal treatment and maximising their quality of life.

Summary

The studies reviewed in this section show that the treatment choices of patients with advanced disease can differ from those with early stage disease. Overwhelmingly, the research evidence shows that terminally ill patients or those with advanced disease are prepared to tolerate high levels of toxicity in the hope of extending their survival chances, even when that probability is firmly stacked against them. However, it is less clear from these studies whether patients with advanced disease wish to fight their cancer despite the odds, or whether their preferences are founded on inaccurate information (Field, 1998). More exploratory studies are needed to identify the role of the clinician in communicating information to the patient with terminal cancer, so that it is clear if patients have an intrinsic need to continue their fight against their disease or whether they are misinterpreting the information that is divulged to them. In addition, a large proportion of the studies have been retrospective in nature and have reported findings that were based on hypothetical scenarios, rather than on patients facing 'real' treatment choices.

The effects of age

It is sometimes assumed that older patients are less likely to play an active role in treatment decision-making. One study found that younger patients were more likely than older patients to seek more information about their disease and treatment, and to participate in decision-making (Cassileth et al, 1980). However, although the study indicated that younger patients wanted to make decisions, the term 'decision-making' had not been defined. As a result it is impossible to determine from this investigation whether younger patients in fact played a more active part in practice, or whether they simply participated in a different way to their older counterparts.

Furthermore, a study by Pierce (1993) found that breast cancer patients over seventy years of age were less likely than younger patients to participate in decision-making. This finding was supported by another study that used individuals currently registered at a Health Maintenance Organisation, where younger and better educated individuals preferred a more 'active' role in decision-making especially in situations where their individual views and values were likely to be important (Thompson et al, 1993). Another recent study also showed that older women with breast cancer were less likely than their younger counterparts to have desired participation in the selection of their treatment or sought medical information (Petrisek et al, 1997).

A different study found in its sample of cancer patients with heterogeneous diagnoses, that older patients sought information about their illness and treatment outside of the clinical setting just as actively as the younger patients (Turkcharles et al, 1997). Sandison et al (1996) found that out of fifty breast cancer patients, thirty-eight made a treatment decision, and the remainder delegated the surgeon to make the decision. At twelve month follow-up only two women were unhappy with their treatment choice. The authors concluded therefore, that elderly women should be involved in deciding on the treatment for their breast cancer. However, the consultations in this study were unusual, since all patients were actively encouraged to make a decision by their surgeons. This may not happen in consultations outside of the research setting, and therefore, the numbers of older patients electing to make their own treatment decision might be considerably lower than evident in this study. Also, this study lacked a comparison group of 'younger' women with breast cancer to assess how far younger and older women played a part in decision-making.

The above studies suggest that although older cancer patients might prefer some degree of involvement in the medical encounter, generally they do not want to participate in treatment decision-making to the same degree as their younger counterparts. Most of the studies have failed to set out clearly the definition of 'decision-making', and also what should be regarded as 'high' and 'low' involvement in decision-making. Thus, more studies are required to investigate if older patients in fact participate less than younger patients, as most studies to date have focused largely

on patients' perceptions rather than behaviour. Again, this issue is important in the case of colorectal cancer due to an increased incidence in old age.

Social/cultural factors in decision-making

Some authors have stressed the importance of considering the impact of social and cultural factors on the treatment decision-making process (Eisenberg, 1979). Studies have reported that patients with serious illnesses, such as heart disease, renal failure and cancer, tend to make treatment choices according to how these fit into their everyday lives and experiences. Kelly-Powell (1997) found in her qualitative study that people with serious illness made treatment decisions that could be incorporated into normal routines with the least amount of disruption. However, the study attached little importance to the significance of clinical factors on treatment choice. Two studies found that when decisions required medical knowledge, most patients preferred to play a less active part in decision-making (Biley, 1992; Thompson et al, 1993). Another study of cancer patients living in a rural setting found that such patients often have to travel long distances to obtain cancer treatment. Consequently, fears of separation from family and friends were very real to them, and affected their treatment choice (Burman and Weinert, 1997).

Another study investigating the relationship between lay beliefs of two Mexican communities and accessibility to Western health care, found that illness beliefs did not influence peoples' decisions to seek health care (Young and Garrow, 1982). Other practical considerations were reported to have played a more central role in affecting peoples' help seeking behaviour. For instance, cost, geographical distance, and perceptions of the effectiveness of treatment. Thus, cultural differences between western doctors and non-Westernised communities do not always affect utilisation patterns (Garro, 1982). As the authors point out, the average person assumes himself/herself to be ill-equipped to overcome a medical problem alone, and relies on the greater technical knowledge of the clinician. Most people have a practical concern regarding health and illness. This study supports much of the research evidence on decision-making in cancer, where most patients prefer to delegate the decision-making task to the expert clinician.

Another study investigating prostate cancer patients' choice of hormonal versus surgical treatment, also found that practical factors, rather than health related concerns, played a large part in their choice of procedure (Chadwick et al, 1991). For instance, half the patients who chose surgery preferred a short stay in hospital rather than commit themselves to a series of monthly

visits. The remaining group of patients who chose hormonal therapy did so primarily in order to avoid a more invasive surgical procedure.

Family constitution has been reported to influence decision-making behaviour in another study which used hypothetical vignettes rather than actual treatment options in oncology (Yellen and Cella, 1995). The study found that the strongest predictor of treatment preference was parenthood status. Having children who live in the same dwelling encouraged patients to opt for more aggressive oncological treatment, even when the likelihood of benefit diminished beyond what many would consider to be clinically reasonable. Pierce (1993) found that the older women with cancer in their study were likely to be unmarried due to the death of a spouse, to be without children in the home, and to be retired. As a result the effects of treatment on family responsibility were less important to them, which is why they were less active in the decision-making process. Hare et al (1992) have shown however, that cancer patients often identified the likely burden on the family as the main factor influencing their treatment choice, whereas their surrogates considered the patient's pain as the most important factor.

Summary

Many of the studies in this section indicate that social factors play a significant role in affecting cancer patients' treatment choices. The inconvenience caused by cancer treatment to patients' daily routines, the potential impact on family and friends, and parenthood status, were often important considerations for patients when faced with treatment decisions. However, many of the studies have paid little attention to the clinical factors in the decision-making process, and it is difficult to estimate how much weight to attach to social and cultural variables in patients' treatment choices. Also, more research is necessary to identify more closely the particular social factors that play a key role in the decision-making process, and how they relate to the specific disease in question. The above studies have placed little emphasis on the impact of disease status and progression on treatment decision-making, which gives the impression that social factors are more important in decision-making. As Kelly and Field (1996) indicate, social research needs to pay more attention to the role of disease, and not only the meanings that people attach to it.

Physician related factors in decision-making

Much of the research, which has been conducted on treatment decision-making, has often focused on how patients reach decisions, with the assumption that they make decisions alone. Very few studies (except in the clinical literature) have paid adequate attention to the role of clinicians in this process. The way in which doctors frame the information that they disclose to patients, or the reasons why they arrive at certain decisions, has frequently been overlooked.

A study conducted in Italy on the effect of breast cancer surgeons' beliefs and personal characteristics on their treatment preferences, found that most surgeons preferred to offer radical surgery than conservative therapy (Liberati et al, 1990). The reasons why surgeons preferred the radical procedure was because they thought that it was more effective than conservative treatment. Those choosing limited surgery appeared to be guided by the consideration that the less mutilating treatment should be offered, given that it is just as effective as the radical option. Studies in Canada (Deber and Thompson, 1987) and the USA (Tarbox et al, 1992), have indicated that surgeons (not oncologists) often prefer radical procedures. Often their treatment choice is attributed to the practice styles of the hospital where the surgeon completed his/her medical training. Liberati et al (1990) found that older patients were more likely to be offered radical surgery, in whom negative cosmetic consequences were judged to be less important than in a younger patient. The research evidence presented suggests that outcome data from clinical trials are not always the most important determining factor in the clinician's treatment preference. Practice related characteristics and personal preference often have an equally important impact on treatment choice (McGrath, 1995).

It has been suggested by some investigations that providing patients with more information can enable them to make more informed decisions, which are more in line with their personal values and goals. One study compared the hypothetical decision-making preferences of college students, before and after exposure to an interactive video educational package and an information booklet (Chapman et al, 1995). The study found that subjects' knowledge scores increased and their preferences changed. Thus, patient education may play not only an informing role but a persuasive one, perhaps even persuading patients away from their real preferences. The main weakness of this study however, was that the subjects were not actual cancer patients. Any conclusions could be problematic, since several other investigations have reported large differences between the attitudes of cancer patients and non-cancer patients towards treatment choice (Slevin et al, 1990; Degner and Sloan, 1992 Chapman et al, 1995).

Another study based on a survey of American breast surgeons, examined whether they believed that modified radical mastectomy was more effective than breast conserving surgery. They found that most believed both procedures to be equal in achieving similar survival outcomes.

Nevertheless, the majority of surgeons presented the mastectomy option to patients as a more effective option (Tarbox et al, 1992). Further evidence suggests that physicians do not always view the discussion of treatment alternatives as an integral part of informed consent (Nayfield et al, 1994). Such views may be particularly problematic in the treatment of early stage breast cancer, where treatment options are available for many patients. However, whether the communication of more 'objective' information to patients can modulate the effects of physician bias, and thus improve the informed consent process, still requires further study.

Some studies have demonstrated that patient demand and not only physician preference, can strongly influence the treatment decision-making task. Certainly, Coulter (1988, 1991) reported that the number of hysterectomies performed by gynaecologists in the UK and abroad showed evidence that patient demand was a crucial determining factor. Thus, decisions to undertake certain procedures can be influenced by patient demand, sometimes without any evidence that the treatment is of any benefit. Other studies on breast cancer have also reported that large variations exist in the treatments which physicians recommend to patients (Deber and Thompson, 1990). In Sweden, social class is directly related to the incidence of appendectomies and tonsillectomies, with people in higher classes undergoing more operations (Allender, 1973).

Sometimes the physician's communication or interaction style has been found to influence the degree to which patients participate in the doctor-patient interaction. Street et al (1995) found in their study, that when the doctor displayed little interest in the patient's views, the patients assumed a passive role in the interaction. The study concluded that physicians can facilitate greater patient involvement in the interaction with the doctor, by asking for the patient's opinion, and by offering encouragement (England and Evans, 1992; Pellissier and Venta, 1996).

Summary

It is evident from the studies reviewed here that clinicians can, and often do, influence the patient's choice of treatment. The literature indicates that the advice that doctors give to patients can sometimes be grounded in personal preference rather than scientific fact. Indeed, some clinicians do not believe that patients are entitled to a description of the treatment alternatives that are available for their particular condition. Other studies have found that clinicians can change patients' stated preferences through the way that they present information. These studies show that the role of the cancer specialist can be critical in affecting the nature of the treatment decision-making process. This supports the case for more research into the role of clinicians in the decision-making task. Most studies have overwhelmingly focused on the cancer patient's

treatment preferences without sufficient attention to the doctor's input. Those studies that have investigated the role of the doctor in decision-making have often only reported on the views of clinicians retrospectively. Further observational research evidence is required to show how treatment decisions are made within the doctor-patient encounter.

‘Framing’ effects

The way in which information is framed by physicians and the way in which risk and benefit is portrayed, can drastically affect a patient's understanding and choice of treatment (Fischhoff et al, 1993). 'Framing' can play an important role in oncology where statistics and probabilities often influence decision-making (Elit et al, 1996), and where the presentation of information can affect patients' recall and understanding (Reynolds et al, 1981).

One component of human judgement is the tendency to categorise an entity as either 'dangerous' or 'safe' without taking into account the level of exposure (Parsons and Atkinson, 1992; Redelmeier et al, 1993; Charles et al, 1998). For instance, some people may believe that vitamins are healthy, and therefore feel that an unlimited intake is not particularly harmful. Also, people may believe that a total elimination of risk is preferable to a reduction of risk, which may explain why so many cancer patients are willing to undergo prolonged high toxicity therapy for a relatively small benefit in survival (Redelmeier et al, 1993; McQuellon et al 1995; Yellen and Cella, 1995; Mazur and Hickman, 1996).

Framing 'effects' are difficult to avoid because there is no one optimal method for presenting statistics. Redelmeier et al (1993) claim that treatment may appear much less attractive when described using mortality rather than survival statistics. Presenting statistical data as the negative consequence of non-compliance to a particular treatment regimen, rather than the positive outcome of adherence, might enable doctors to be more persuasive in recommending a certain treatment protocol to a patient. In addition, knowledge of the outcome of a particular procedure or treatment can also affect peoples' perceptions of risk when choosing a treatment. One study investigated the influence of alternative explanations by doctors about one medical intervention – intubation and ventilatory support (IVS) (Mazur and Hickman, 1997). Patients were randomised to receive a general explanation or a detailed explanation by their physician. The results of the study showed that patients receiving the general explanation were willing to accept significantly fewer days of IVS. This indicates that the type of explanation given by clinicians may dramatically affect the patient's choice of treatment.

In another study, reviewers were asked to judge the appropriateness of care in surgical cases that involved an adverse anaesthetic outcome (Fischhoff, 1975). The patients' outcome was described as either 'permanent' or 'temporary'. The reviewers were more likely to rate the quality of care as 'less than appropriate' if the outcome was permanent rather than temporary. Thus, the nature of the outcome influenced the severity of the rating. The study concluded that people were more likely to indicate that a given outcome was a mistake if it was followed by an adverse consequence. In cancer care, informing patients of the likely or potential consequence of treatment may enable them to decide with greater confidence whether they had made the right choice. Doing so may promote a more proactive attitude about untoward medical events, lessen the chances of subsequent distortions, and prevent negative evaluations of treatment choices.

Another study investigated the impact of the presentation of survival data on patient preferences, in a hypothetical scenario (Mazur and Merz, 1993). The findings showed that the preference elicitation process itself affected patients' choices. Patients were presented with a graph comparing better short-term survival versus better long term survival for a hypothetical treatment scenario. Patients over the age of 65 were more likely to opt for a better short term survival curve, and those under the age of 65 were more likely to select the better long-term survival option. Overall, more educated patients were less likely to choose the short-term survival option.

Other authors have observed that the medical profession is not alone in 'framing' patients' perceptions of the effectiveness of cancer therapy. The difficulties created by the complexity of cancer treatment is exacerbated by the hopeful image presented in the scientific literature as well as the media (McGrath, 1995). Research findings are often expressed in terms of a 'breakthrough', which may not be reflective of actual progress. The presentation of unrealistically hopeful expectations does not take into account the side effects, which many of these new treatments may inflict on patients.

A qualitative study on breast cancer patients' treatment choices was conducted by Pierce (1993). The study found that patients tended to break down the treatment alternatives into more manageable parts. Patients did not usually consider all the attributes of all the alternatives. Instead, they preferred to consider selective subsets of the information given to them, and which appeared particularly relevant to them during the decision-making task. The findings were similar to those of Charles et al (1998), who also conducted a qualitative study of breast cancer patients, and found that patients needed to interpret risk information by simplifying it into more manageable dichotomous concepts, such as 'high' or 'low'. This enabled them to reach a more meaningful decision.

Summary

It is evident from the above studies that the way that information is framed by a doctor can dramatically affect the patient's understanding of the decision-making problem. For instance, the presentation of scientific information with an emphasis on the negative rather than the positive consequence of a certain treatment option, can be used to persuade patients in a particular direction. Central to the decision-making process in cancer care is the way that information is communicated to, and interpreted by the patient. However, to date only a small number of studies have investigated how cancer patients interpret scientific information. The process of clinical decision-making is increasingly being influenced by scientific research evidence, and therefore, the way that such information is communicated to patients could have a profound effect on the decision-making process. The studies reviewed in this section are again largely based on hypothetical situations. So much more prospective research needs to be carried out to investigate the perceptions of cancer patients who are in the process of making treatment decisions. As noted in the previous section, there is an urgent need to study not only the way that patients interpret probabilistic information, but also the way that information is communicated by the clinician.

Methodological issues and conclusion

What is missing in the literature?

This final section provides an overview of some of the methodological issues that were identified in the research literature on treatment decision-making.

The majority of research studies that have been carried out to date on the treatment decision-making process, have largely focused on the preferences of breast cancer patients, and their involvement in decision-making. These studies have tended to investigate how patients make choices among several different treatment alternatives, rather than on their reasons for accepting or refusing treatment per se (Wilson et al, 1988; Ganz et al, 1992; Long, 1993; Chapman et al, 1995). As a result, studies have often assumed that cancer patients play an 'active' part in selecting their treatment. In fact, recent studies have shown that often patients prefer to delegate the

decision-making responsibility to the doctor (Degner and Sloan, 1992; Fallowfield, 1997; Charles et al, 1998).

A large number of studies have also failed to explore the views of 'real' cancer patients facing 'real' decisions. Many studies have presented hypothetical scenarios to both cancer patients and non-cancer patients. This is laden with difficulties because there is evidence to suggest that patients facing real decisions often make different choices to those not facing actual decisions (Beaver et al, 1996). Thus, findings obtained from investigations of non-patients or hypothetical scenarios should be interpreted with caution.

Studies investigating patient involvement in decision-making have produced contradictory results due to the lack of consensus on the definition of 'decision-making'. Studies have often confused the patient's need for information with treatment decision-making (Sutherland et al, 1989; Pierce, 1993). Patients may often play an 'active' part in the doctor-patient encounter but that does not necessarily mean that they are participating in the decision-making process. Furthermore, there are often different degrees of participation or involvement in decision-making, and most studies have tended to use very 'static' definitions of the two concepts. For instance, patients were often considered to be involved in decision-making, or not involved in the process (Cassileth et al, 1980; Blanchard et al, 1988). Similarly, the definition of 'shared' decision-making has often been used very loosely by different studies. Some studies have referred to 'shared' decision-making as a process whereby the patient delegates the decision-making problem to the doctor (Ward et al, 1989; Johnson et al, 1996). Other studies have even defined a 'shared' approach as one where patients interact with the doctor 'reactively' rather than 'proactively' (Siminoff et al, 1989). Other investigations define 'shared' decision-making as a state where patients actively seek information from the doctor but do not play a commanding part in actual treatment decisions. Thus, 'shared' has been defined to mean an information seeking task, rather than a decision-making task (Strull et al, 1984). Clearly therefore, many studies have used different definitions for the term 'decision-making' or 'participation', often leading to conflicting results. Recently however, studies have started to identify the distinction between information needs of cancer patients and their actual involvement in decision-making (Luker et al, 1996; Degner et al, 1997; Graydon et al, 1997).

A further weakness in many research studies investigating the decision-making process is the tendency to investigate the views of patients without paying adequate attention to the role of the doctor. Consequently, the input of the clinician and the clinical context in which decisions are made has frequently been left unexplored. Therefore, many studies have tended to describe a one-dimensional view of the decision-making process. Charles et al (1998) for instance, conducted a qualitative study on the views of patients with early stage breast cancer, on their involvement in treatment decision-making. This study concluded that patients often interpreted the information that they were given, solely with reference to their everyday experiences and lay beliefs.

However, the study failed to demonstrate the input of the clinician in interpreting this information.

Types of studies conducted on decision-making

Many of the studies conducted on patient involvement in treatment decision-making have largely adopted structured approaches, questionnaires, vignettes, 'role-indicators', as well as decision-analysis methods. Also, a large proportion of studies tended to be retrospective and hypothetical, which means that much of the research evidence is based on previous rather than current experience, and on patients who are not facing 'real' decisions (Sutherland et al, 1989; Llewellyn-Thomas et al, 1991). The problem with these studies is that often patients can express different views about decision-making with the benefit of hindsight. Equally, patients who are not faced with real life decisions, may express different views to individuals who are faced with real treatment choices. Therefore, there is a need for future research to explore prospectively the decision-making behaviour and views of cancer patients.

In addition, there is a shortage of studies investigating the 'process' of decision-making. Many studies focus on patients' views about the decision-making process, without studying how decisions are made, and how information is exchanged between the doctor and the patient in actual face-to-face interactions. Consequently, there is a need for a concerted effort to investigate the doctor-patient interaction, and how decisions are made within the medical encounter. Certainly, the decision-making task is sometimes a prolonged process, whereby the patient may require several visits to see the doctor in order to explore the pros and cons of the different treatment options. Sometimes, the doctor may be unclear on the best treatment for a patient, which could involve having to carry out investigations and tests before a full account of the patient's condition is available. Thus, the common difficulties as well as the practicalities inherent in the treatment decision-making process should be explored in greater depth. Many studies have tended to focus more intensely on the reasons why patients choose one treatment rather than another, without exploring the problems, which inhibit or affect the decision-making task.

In essence, there is a lack of in-depth exploratory studies that seek to investigate the views of patients, doctors, and relatives, all of whom play a central role in the decision-making process. In particular, there is a tendency for research studies to dismiss the part played by the patient's family and friends. Only a handful of studies have explored the family's part in decision-making, especially in cancer (Labrecque et al, 1991; Marvel et al, 1994; Benson and Britten, 1996).

The studies that have been carried out on treatment decision-making in cancer can be divided into three broad strands. Firstly, the clinical studies have largely been concerned with assessing the impact of various treatment regimens on patient survival. Thus, these studies have been less concerned with the treatment decision-making process, and more interested in studying the management of disease (Labianca et al, 1997; Parshad, 1997; Bleiberg, 1998; Cady et al, 1998; Violi et al, 1998; Wils, 1998). Secondly, many studies have investigated the patient's sources of information, participation, and decision-making preferences. These studies were largely conducted on breast cancer patients, and often involved using questionnaire or survey designs. These studies have investigated the impact of age, information disclosure, socio-cultural factors, physician-centred factors, and patients' desire for involvement in the decision-making task. Thirdly, a large volume of research has been conducted on cancer patients' psychological adjustment to their illness and the impact of treatment on their quality of life (Morris and Ingham, 1988; Ferrel and Rivera, 1995). More specifically, some studies have investigated the direct impact of cancer treatment on patients' psychological health and coping behaviour. These investigations, which were carried out primarily on breast cancer patients, also focused on the psychological impact of illness on patients' treatment preferences (Wilson et al, 1988; Fallowfield et al, 1990; Slevin et al, 1990; Ganz et al, 1992; Long, 1993; Schover, 1995; Williams, 1995). Many of these studies found that psychological factors play a central role in influencing patients' decision-making behaviour.

The treatment decision-making process in breast cancer has been widely studied. However, other cancer sites have received scant attention in past research. This trend is reflected in the small number of studies investigating treatment decision-making carried out on patients with colorectal cancer.

Conclusion

The aim of this literature review has been to examine the research studies that have been carried out on the information needs and decision-making preferences of patients, particularly those suffering with cancer. Initially, a background of the current colorectal cancer literature was provided. The review demonstrates that much of the research in colorectal cancer has focused on screening programmes and their cost-effectiveness (Leard et al, 1997), the psychological responses to screening (Schraub et al, 1995; Graupe et al, 1996), and the impact of treatment on survival and disease response (Decossee and Cennerazzo, 1997; Ulander, 1997; Whynes and Neilson, 1997; Anderson and Palmer, 1998; Cady et al, 1998; Violi et al, 1998). The majority of these studies have been concerned with investigating clinical response to treatment and screening

programmes. There is, therefore, an urgent need to carry out further research on the decision-making preferences and practices of patients with colorectal cancer and clinicians.

An overview of the main theoretical models representing the doctor-patient relationship was provided. The research literature on patient participation in the medical encounter was reviewed. The research indicated that patients and relatives are playing a more active part in the doctor-patient encounter.

The research evidence on cancer patients' information needs showed that patients want to be well informed in most cases, and many hold clear views about the type and volume of information that they desire. In recent years, patients have started to expect to be given more information. However, the research evidence identified certain barriers that exist in the communication process. For instance, sometimes information is not communicated adequately to cancer patients, and many physicians still have problems deciding on what information to disclose. The literature indicates however, that some patients are selective about what they want to be told, and not everyone desires all the information. Indeed, cultural factors play an important part in shaping patients' expectations of what to expect from their clinician. Also, the research literature indicates that large national and inter-national variations still exist in physicians' attitudes towards the disclosure of truth to cancer patients. It has been reported that doctors sometimes do not disclose enough information to cancer patients, or they fail to resolve patient uncertainty. Moreover, the ever more complex nature of cancer treatment presents difficulties for doctors in deciding on how to communicate complex concepts to patients in simplified form (Marmot, 1996).

The research evidence strongly suggests that cancer patients often prefer to delegate the decision-making task to the clinician, since they prefer to share the responsibility for the decision. The review further identified the need to make a distinction between studying patients with early and advanced disease, since the implications for decision-making are significant. Patients with advanced disease may perceive their situation in a different light to the way that patients with early cancer view their situation. The literature also shows that cancer patients often make treatment choices in accordance with their domestic and social circumstances. The convenience of attending for treatment, or the availability of transport, can sometimes affect patients' treatment decision. Also, the clinician's personal preference or expertise with one particular procedure may affect the way that the treatment recommendation is framed to the patient.

CHAPTER 3

METHODOLOGY

Introduction

This chapter describes the research methods which were deployed in the study, discusses why they were used, and sets out the problems which were encountered during the course of the fieldwork. It is necessary to provide an account of the research process as a means of placing the subsequent analytical chapters in a meaningful context. This chapter describes the challenges which were encountered whilst conducting the fieldwork, and evaluates the strengths and weaknesses of the methods that were employed. Issues of access to the research setting and the way that 'informed consent' was obtained from patients, will also be discussed.

Study aims and objectives

Before discussing the access process, the aims of the study will be described so that it is evident why the research setting was chosen, and why the particular study population was selected.

Main Research Questions	Methods Likely To Obtain Desired Data
What are patients' perceptions of treatment decision-making?	1. In-depth interviews with patients
To investigate the process of decision-making	1. In-depth interviews with patients 2. Observations of consultations
How information is transferred to the patient and what are patients' information needs	1. In-depth interviews 2. Observations of consultations
How might wider and immediate organisational factors affect the delivery of cancer care and treatment decisions?	1. Interviews with oncologists, nurses, and contracting staff at Avon Health Authority 2. Documentary data on Avon Health Authority's contracting policies and other policy documents.

The study set out to investigate four inter-connected questions relating to the way in which treatment decisions are carried out at the Bristol Oncology Centre. The first question the study aimed to investigate was patients' perceptions of the decision-making process. The most appropriate approach was to employ in-depth interviews with patients so that their views about their involvement in the decision-making task could be explored in detail. This information could have been obtained using a more structured format, such as a questionnaire, although the same depth of responses would not have been obtained. A questionnaire or a survey approach would have benefited a study with more defined, and perhaps less exploratory research objectives. The second objective of the study was to investigate the *process* of treatment decision-making. This would require an understanding of both the clinician's and the patient's role in the decision-making process, as well as their individual perspectives on how decisions are reached. One of the most effective ways of studying processes or behaviours through time is with observation methods. Actors can be observed simultaneously and the decision-making process can be viewed directly. This has the benefit of providing data on actual behaviour, rather than relying solely on the views obtained using questionnaires or interviews. Thus, in order to explore the processes inherent in decision-making, observation methods and in-depth interviews can provide data which

not only shows patients' and doctors' perceptions of the decision-making task, but also their direct role in that process.

The third question seeks to ask how information is transferred from the clinician to the patient, and what are patients' information needs. This question is investigated using in-depth interviews and observation methods so that patients' information needs are understood within the context of their role in the consultation with the oncologist. This way the relationship between the information that patients desire, and the information which they actually receive in the consultation can be compared. Thus, the interviews and the observation methods help to bridge the gap between what informants say and what they do.

Finally, the study attempts to place the findings within the wider organisational context of cancer care delivery. The study will seek to establish how current national and regional policy in cancer care, might impinge on the organisation of care and decision-making within the Bristol Oncology Centre. A wide range of data collection methods are required to address this question, since observations and interviews may only provide limited information about the wider organisational constraints and processes. The data on the more immediate context of the Oncology Centre was obtained from interviews with oncologists and nurses. Information on the wider influences was derived from interviews with contracting staff at Avon Health Authority, policy documents, and other research papers documenting regional and national cancer policy. Thus, the aim is to provide not only the organisational context of cancer care, but also a policy context.

Access

The process of obtaining ethical approval from the United Bristol Healthcare Trust (UBHT) Research Ethics Committee, was a protracted one. The first application was refused, on grounds that communicating with patients shortly after their diagnosis could potentially evoke anxiety and distress. This highlighted the sensitive nature of the study and the potential harm that could result if interviews did not address these sensitive issues with care. However, the revised application emphasised that all patients would be given the choice to refuse participation in the study, and interviews would be limited to discussing 'treatment decision-making'. Following this, approval was granted.

Social access

'Social access' refers to the extent that the 'gatekeeper' (in this case, the oncologists and the nurses) can establish trust in the researcher. Often, researchers who are 'strangers' in a social setting hold very few bargaining tools, which can prevent a researcher gaining access through reciprocation. The extent to which the 'gatekeeper' chooses to drive a 'hard bargain' may be related to how far he or she is prepared to trust the researcher (Luhmann, 1979; Lee, 1993). 'Gatekeepers' may be prepared to invest a high degree of *interpersonal* trust in the researcher by granting access to patients. However, they may also want to establish a certain amount of *impersonal* trust with the researcher. This was made explicit when the oncologist asserted a desire to exercise ultimate discretion over the selection of patients for the study, if their suitability was questionable. Securing 'social access' was an ongoing process, requiring frequent contact with oncologists and nurses to 'negotiate' access to patients. Frequent staff changes also meant that contact with 'new arrivals' had to be maintained. Thus, establishing a good rapport with the relevant members of staff throughout the course of the fieldwork, was critical for gaining subsequent access to patients.

Access to patients

Once 'physical access' and 'social access' had been secured, the final step was to establish access to patients, which involved requesting their agreement to participate in the study.

Establishing some kind of initial contact with cancer patients was crucial for recruitment purposes. Patients who came to the outpatient's clinic for the first time were approached. I adopted the role of shadowing one of the oncologists at the clinic, and patients were able to relate to me more easily and perhaps were less suspicious of my intentions. At the consultation the doctor often introduced me as a researcher, and asked if patients had any objections to my presence. Notes were made during the course of the interaction, following which patients were approached and invited to participate in an interview.

It was important to be seen to be attached to the consultant as this provided me with a legitimate role. Several months into the fieldwork I started to become 'less visible' as I 'merged' into the setting (Lee, 1993). Having spent one year in the oncology centre I had time to see how the department was run and what roles various members of staff carried out. To an extent therefore, I was 'socialised' into the working environment where my role became legitimate and recognised

by staff members. Cannon (1989) experienced a similar type of socialisation in the hospital in which she was working, whilst conducting an ethnographic study of women with breast cancer. In her case, the medical staff created a 'legitimate' role for her in order to resolve the problem of incongruity of her status among them. Cannon states:

The fact that I was a sociologist was not in itself sufficient, in the staff's eyes, to legitimate my position. This was demonstrated later on by their attempts to 'draw me in' as a sort of counsellor or mediator in their own dealings with patients...(Cannon, 1989, p.11).

The ability to demonstrate a 'legitimate' role in which the fieldwork is conducted is extremely important, otherwise staff members may become suspicious or even obstructive. As Lee (1993) argues, the legitimisation of a researcher's presence is a 'progressive' process, and one which involves the transformation of the researcher's cultural identity from that of untrustworthy, to that of trustworthy, by demonstrating membership and participation within the social group.

'Informed consent' or 'process consent'?

The next step in securing 'patient access' was to arrange an appointment for interview. Certainly, my attachment to the consultant oncologist helped a great deal in securing co-operation to patients. In order to strengthen the ethical integrity of the study, patients were reassured that the information that they disclosed was confidential, to which nobody (including the doctors) had access apart from myself and the patient. Patients were told that they could stop the interview at any time, or refuse to participate in any future interview for which they did not have to give a reason. 'Informed- consent' can be a static, past tense concept which is often incongruent with the ongoing, dynamic, and changing nature of qualitative research. In order to overcome the 'static' nature of informed consent this study provided patients with the option of 'process consent'.

The intent of the process consent is to acknowledge the dynamic and emergent nature of the research design, include the initial input and suggestions of the participants in the study, and negotiate further input regarding changes over time (Raudonis, 1992, p. 6).

The inclusion of 'process consent' in this research design was an attempt to overcome some of the ethical dilemmas inherent in investigating the experiences of cancer patients using qualitative

methods. The following sections will provide an overview of the research and discuss the relevance and application of the research methods to the study aims.

The research setting

Background

The oncology centre is a large specialist department exclusively concerned with the treatment of cancer patients. It is a large regional cancer centre, which receives referrals from district hospitals in Avon and Somerset. The Bristol Oncology Centre receives referrals for most common cancers, including breast, lung, cervix, skin, lymphomas, and colorectal cancer. The recommendations set out by the Expert Advisory Group on Cancer (Calman-Hine, 1995), have stressed the importance of site specialisation. Following the Calman-Hine report, Bristol Oncology Centre has pursued this policy to actively encourage the treatment of cancer by clinicians who have the relevant expertise.

The Bristol Oncology Centre plays an important role conducting clinical trials on palliative care services, as well as on other new developments in the treatment of cancer. ^bBetween April 1997 and April 1998 a total of 161 patients were entered into clinical trials. On the whole, colorectal cancer patients who are referred to the Oncology Centre tend to have more advanced disease, for whom further treatment has greatest benefit.

The Bristol Oncology Centre was chosen in order to study treatment decision-making at a certain point in a patient's illness. The types of patients attending the oncology centre are typically a selective group, who are likely to be different in some respects to patients who are not referred. However, the management of colorectal cancer is broadly similar across the country, in that most patients undergo surgical resection followed by additional chemotherapy and/or radiotherapy treatment. Therefore, the findings generated from this study setting are likely to be transferable to other similar settings.

The oncology centre in Bristol is one of several (approximately 13) tertiary referral centres across the South West of England typically providing chemotherapy and radiotherapy treatment for common cancers, as well as palliative care services. The Bristol Oncology Centre is unique in the South West region because it provides specialist cancer services for a population of one million. Other oncology departments in the South West provide more limited cancer care to a

^b Clinical Trials Unit, Bristol Oncology Centre, 1998

smaller population. Some of these smaller cancer departments typically hold a more limited budget than the Bristol Oncology Centre, and are restricted in the range of treatments that they can offer to patients. Cancer care is in the process of radical change, whereby small oncology departments which only provide a limited service to small numbers of patients, are becoming integrated into larger Cancer Centres and Cancer Units, as a result of the Calman-Hine recommendations (Calman-Hine, 1995). As a result cancer services are currently being reorganised to offer care from larger specialist units which are geographically centralised. Progressively therefore, cancer treatment will be centralised in catchment areas with large populations, so that expertise can be maintained and resources used more efficiently. Such Cancer Centres and Units are essentially organised on a 'hub and spokes' basis, where essential secondary care is provided by large regional and district hospitals, and peripheral small local hospitals alongside primary care teams will provide palliative, follow-up and routine care.

The sample

The study population was chosen on the basis of a 'convenience' sample. Patients, who came to the oncology clinic for the first time, were approached after their consultation with the oncologist. Altogether 87 consultations were observed, 32 were patients attending for a follow-up appointment, and 55 first time attendees. In addition, 55 new patients were approached for an interview and 37 agreed to participate, resulting in a response rate of 67%. Patients who were approached to participate in an interview were determined by the numbers attending the weekly outpatients clinic. Refusers were more likely to be male and over 65 years old, whereas participants comprised a larger number of females and patients under 65 years of age. Every new patient attending the clinic was asked to participate thereby, minimising selection bias.

All new presentations to the oncology centre were recruited consecutively from caseloads of one oncologist responsible for the care of colorectal cancer patients. Eligible patients were firstly approached by the consulting oncologist, and asked whether they were willing to participate in an interview. The study was explained and an information sheet with a reply-slip was issued to each patient requesting their response by post (Appendix 1). Only new presentation patients were approached for an interview, since the study aimed to conduct observations of the initial discussion about treatment choice between the oncologist and the patient. The observations could then be connected thematically to the subsequent interviews conducted with the same patients. This way, the findings from the observation and interview data could be used together for theory and theme development.

The interview sample consisted of 24 males and 13 females, and the average age for men was 68.75 years and for women 61.3 years. Most patients attending the oncology centre had undergone surgical resection of their cancer, and the main purpose of their attendance was to discuss the possibility of treatment by chemotherapy or radiotherapy. Colon and rectal cancer is classified according to the *Duke's classification system, which ranges from Duke's A to D. For more detail of patient characteristics refer to chapter 5.

Data collection

Observation methods were employed to investigate oncologist-patient interactions during clinics. Notes were made verbatim during consultations and subsequently, in order to draw out themes and make theoretical comparisons. Immediately following the clinic, detailed descriptions of each observation episode were recorded, and notes were subsequently coded using a coding frame (Appendix 3). The majority of observations conducted were of consultations between patients presenting for the first time and oncologists. However, observations of follow-up consultations were also carried out (32 in total). The purpose of employing observation methods was to obtain data on the *process* of decision-making, and to examine change in the decision-making practices of patients. Comparisons were made throughout the course of the fieldwork between the observation and the interview data, in search of common themes.

Since many of the consultations were fairly brief, it was difficult to record entire conversations verbatim, and therefore, notes were made on the interaction immediately following the consultation. Initially, the observations focused on the way that treatment decisions were reached between doctor and patient. However, further on in the fieldwork new emergent themes guided subsequent observations. Thus, the whole process of data collection was developmental, and interviews often focused on specific conversations which patients held with the oncologist. This way the observation data enabled subsequent interviews to focus on detail, which was specific to the patient who was being interviewed. Indeed, on various occasions the conversations recorded in observation notes were used during interviews to jog patients' memories and discuss the

*Cancers diagnosed as Duke's A indicate an early tumour which invades the submucosa (the layer of tissue lining the muscle wall). Duke's B stage cancer is one that invades the muscle wall (muscularis propria), but does not extend beyond this region. Duke's C stage tumours are those which extend beyond the muscle wall of the colon or rectum, and are regarded as 'advanced stage', introducing a potential threat of lymph node involvement. Finally, Duke's D tumours are advanced disease with a high likelihood of lymph node infiltration by the cancer. This stage of tumour invades other organs or structures.

1

decision-making process as it related to the conversation, which they had with their oncologist. Thus, the observation methods often provided a greater focus for the interviews and also made it possible to identify differences and similarities between the views of oncologists and patients. Since various studies have shown that many problems between doctor and patients stem from a breakdown in communication, this study was able to trace some of the specific difficulties inherent in this process (Reynolds et al, 1981; Hinds et al, 1995; Vanwersch et al, 1997).

Data were also collected using in-depth interviews with patients at two points in time: shortly following their decision to undergo further treatment, and five months subsequently, in order to record time trends in patients' views and preferences. Permission was obtained to audiotape the interviews and all patients were assured that the interview recordings would be kept confidential. The aim of the interviews was to explore each patient's experience of the treatment decision-making process. Each interview began with a general question about the patient's views about cancer treatment, progressing onto other issues as the interview gathered pace. Patients were encouraged to talk at their own pace and express themselves in a way, which they felt was most comfortable. This was encouraged so their views of decision-making could be related directly to their own personal history and social context.

The interview process was largely non-directive in that informants were not asked pre-determined questions. An interview guide (Appendix 5) was used at each interview to probe informants about certain issues. Each interview focused on two main issues: treatment decision-making, and patients' information needs. Thus, interviews proceeded in a way, which allowed informants to cast their own perspective on these two issues. Informants were probed in order to clarify issues, or to test themes previously found in earlier interviews. Most interviews typically lasted over sixty minutes, and all were conducted in the patient's home.

Reasons for employing 'participant observation' methods

The social world, according to the phenomenological tradition in social science, is not fixed but dynamic and changing. In order to understand this dynamism and the stages through which social actors constantly pass, it is necessary for researchers to participate in social relations, and seek to understand the actions of the participants within their social setting (Frankenberg, 1980; May, 1993; Pope and Mays, 1995).

There are four basic 'observational roles' that are most frequently adopted by field researchers. Firstly, the 'complete participant' who attempts to engage fully in the activities of the group under investigation. Secondly, the 'participant as observer' adopts an overt role and makes his or

her presence and intentions known to the researched. Thirdly, the role of 'observer as participant' slowly moves away from the idea of participation to one of non-participation. Here, the researcher does not spend much time in the field in order to familiarise himself or herself with the rules, roles, and relationships within the setting observed. Finally, the 'complete observer' is a non-participant role where the researcher is completely removed from observed interactions, and where a mechanised system of recording is adopted (Gold, 1958). Certainly, in practice no researcher can adopt these roles exclusively in the way they are described. Instead, there are degrees of participation or non-participation. The role which I assumed in the clinic could be described as 'participant as observer' to a large extent, whereby my intentions were disclosed to all the members of staff working at the clinic, as well as to all the patients who were involved in the study.

One advantage of observational methods is that they can help to overcome the discrepancy between what people say and what they actually do. This method can circumvent the biases inherent in people's accounts of their actions, caused by a wish to present themselves in a good light and so on (Pope and Mays, 1995). Silverman similarly argues that if ethnography reduces social life to the definitions of the participants, it becomes a purely 'subjectivist' enterprise which loses sight of social phenomena. Instead, the point is to narrow the focus to what people are *doing* (Silverman, 1993). Such a method is particularly useful when used in combination with semi-structured or in-depth interviews. As May points out, unstructured interviewing can illuminate the researcher's understanding, and provide information which is simply not available through observation (May, 1993). Becker and Geer (1970) argue strongly in favour of observational techniques, which they claim can enable the interviewer to check description against fact. That is, they can allow the researcher to cross check statements made by an interviewee against empirical observations (Becker and Geer, 1970). One could argue that observational methods can help to overcome problems of inference, and resolve errors which arise from the necessity of making assumptions about the relation of interview statements to actual events.

We must assume, when faced with an account or transcription of an interview, that we understand the meaning of the everyday words used, that the interviewer is able to talk about the things we are interested in, and that his account will be more or less accurate...these assumptions do not always hold and that the process of inference involved in interpreting interviews should always be made explicit and checked against observation (Becker and Geer, 1970, p. 140).

It can similarly be argued that observation methods are dependent on interview data to provide a greater insight into the meaning of people's actions, or to gain a better understanding of the meanings that they ascribe to phenomena. Indeed, participant observation following

phenomenology, has been criticised for not paying enough attention to people's feelings, beliefs and emotions, instead it has tended to focus on features such as 'process' and 'behaviour'. However, it can equally be argued that 'process' and 'behaviour' are factors largely neglected by unstructured interviewing. Observation methods can provide valuable data concerned with looking at *change*, which is a process that interviewees are likely to experience difficulty describing (Becker and Geer, 1970). A person who is in the midst of change may not be able to describe what is happening or interpret the nature of such change. Thus, interviews are often less effective in providing information concerned with 'process' and 'change', than observation methods, as May suggests: "a questionnaire asks questions at one particular time. It is a static-causal snapshot of attitudes; how and why people change is not understood" (May, 1993, p. 113).

Conducting clinic observations

Once in the research setting, I needed to decide what would be observed and how the observations would be conducted. May (1993) indicated that attempting to record everything and anything is impossible and analytically undesirable. Observations of consultations were carried out to identify recurrent themes, which would subsequently be refuted or supported by future observations. If they happened to be refuted then I would search for other themes during future consultations and subject themes to further testing. This is a method often referred to as 'theoretical sampling' (Glaser and Strauss, 1967).

A further important issue requiring mention is the way in which observations are recorded. The comparability of data is an important requirement of the information, which is collected using qualitative methods. The ability of the researcher to compare the different accounts or transcripts is of great importance for future analysis as well as for the internal validity of the data. The main purpose behind comparing different accounts is to check how far emergent themes are applicable to other cases. Comparing data is also important for the generation of theory ('substantive' and 'formal') especially when adopting the 'grounded theory' method for the collection and analysis of data (Glaser and Strauss, 1967). Participant observation is often a very routine task, which involves repetitive observations and detailed note taking. However, the routine which was followed whilst conducting the observations was critical for obtaining *systematic* data (Gans, 1980). The routine of going to the Oncology department twice a week for over a year, sitting in on consultations, writing notes, interpreting them and drawing conclusions from them, whilst trying to maintain conversations with staff members and patients was often quite demanding. However, it became necessary so that the data were recorded consistently.

Before the researcher can collect 'good' data it is important to learn the 'language' of the group under investigation. May (1993) suggests that understanding the language of a community or social group is a fundamental prerequisite of what he terms *social consensus*. This is the extent to which the observer is able to indicate how the meanings within a culture are shared among people. This can only be achieved through direct exposure over time in the culture one is investigating, and exploring how and in what context meanings are conveyed.

Since the observations and the interviews were conducted in tandem, the development was more prolonged. Having reached the point where subsequent observations would not have contributed to the thematic development of the data, the fieldwork was stopped. One advantage of observing a large number of interactions between doctors and patients was that it allowed plenty of scope for generating themes and exploring connections in the data. Also, it served to add confidence to the data collection task since frequent and recurrent patterns could be supported consistently with examples.

Learning the language of oncology

Entry into an unfamiliar setting can pose many initial problems for the researcher. One such problem is the need to obtain the trust and support of the people who are already present in the setting. The problem of 'social access' has been discussed earlier, however, 'access' to a social group or an organisation is an ongoing process that requires 'negotiation' with the people who live or work in the research environment. To this extent the 'negotiation' of 'social access' is inherently linked to the ability of the researcher to speak the 'native language' of the group he or she is investigating. Becker and Geer (1970) have stated that:

Any social group will have to some degree a culture differing from that of other groups, a somewhat different set of common understandings around which action is organised, and these differences will find expression in a language whose nuances are peculiar to that group and fully understood only by its members (p. 134).

Often the language of medicine found its way into the everyday language of patients, and so it was important to obtain a good understanding of the experiences of patients at the oncology centre. Becker and Geer (1970) have suggested that participant observation techniques provide an opportunity to learn the meanings of words used by a social group through the study of their use

in context. This process of learning the language of oncology was a lengthy one, as it involved the need to comprehend medical *concepts*, as distinct from medical terminology.

Members of staff were often asked questions about various aspects of patient management in an effort to test the themes that emerged from the observations. Indeed, Becker and Geer (1970) argue that participant observation can help to generate research hypotheses where none would otherwise have been explored.

Emotional attachment

The consultations with patients were often emotionally charged, and witnessing such consultations can also have a significant effect on the participant observer. Cannon recognises the importance of ‘collaborative interviewing’, a process which recognises the feelings and reactions of the researcher in response to the research experience. She claims that this is the best way of obtaining the most meaningful data from the respondent’s point of view and improving its internal validity (Cannon, 1989). The point being that if the researcher can record what she/he experienced as a result of interviewing a respondent, or observing a phenomena, then a more complete account of the phenomena can be retained. However, it is also necessary for the researcher to spend time away from the field in order to evaluate how far s/he is affecting the setting, and consider the extent to which the data is being distorted by such involvement (Gans, 1980).

Semi-structured interviews

Unstructured or semi-structured interviews address different questions to those addressed by quantitative research, in that the former are more concerned with ‘depth’ and ‘flexibility’, and the latter with ‘replicability’ and ‘structure’. Britten (1995) supports this point with the view that qualitative interviewers attempt to keep their agenda flexible when interviewing respondents. She claims that they attempt to explore what people have to say in as much detail as possible, and uncover new areas that were not anticipated at the outset of the research. Similarly, Burgess (1980) claims that the qualitative interview is unstructured but at the same time it is ‘controlled’, and provides an opportunity for the researcher to probe deeply and open up new dimensions of a problem. Lee (1993) supports this claim by stating the following:

The survey assumes that social phenomena have an external, stable and verbalisable form. It is therefore an inappropriate instrument for investigating aspects of experience which are internal, fluid or expressed in non-verbal ways...In contrast, in-depth interviews provide a means of getting beyond surface appearances and permit greater sensitivity to the meaning contexts surrounding informant utterances (p. 104).

One of the most striking differences between qualitative interviews and structured interview methods (questionnaires or survey methods) is the degree of personal investment required of the researcher in the interview situation (Lee, 1993). Denzin (1993) claims that the unstructured interview gives greater depth since it is based on a sustained relationship between the informant and the researcher. Other authors have described a method of interviewing, which is called 'collaborative interviewing' where the researcher can experience 'countertransference'. This is a state where the interviewer develops feelings in response to the interview experience (Laslett and Rapoport, 1975). The authors argue that far from rendering the research 'impressionistic', the process of 'countertransference' helps to obtain the most meaningful data from the respondent's point of view whilst strengthening the internal validity of the interview data (Cannon, 1989).

Researching a sensitive subject such as cancer can be very demanding on the researcher, and his/her personal involvement can affect the way in which the researcher reports the data. So there is a very real issue of interviewer bias in any situation where there is the likelihood of heavy personal involvement of the researcher in the people he/she is studying. (The next section discusses some of the practical difficulties inherent in 'interviewer bias'). Lee (1993) contends that the desire to understand the perspective of the deviant groups and to work with the disadvantaged can lapse into a 'romanticised identification' with the underdog. A dilemma that is difficult to resolve. Lee goes even further to say that when conducting in-depth interviews:

The interviewee develops an identification with the interviewer or vice versa. As a result, respondents may produce what it is assumed the interviewer wants to hear, or interviewers may accord particular features of the respondent's experience undue prominence (p. 162).

Silverman on the contrary argues that the accounts of the researched as well as the researcher are part of the world they describe. So it is not always necessary to treat respondents' accounts (or the researcher's interpretations of those accounts for that matter) as if they were scientific statements and subject them to possible refutation (Silverman, 1993). Further, the question of how far the researcher can trust the accounts of his/her informants is not always a valid one according to the

interactionist tradition. This tradition supports a way of studying people's accounts which goes beyond classifying them as true or false. As such, the researcher's role is not to simply uncover a particular sentiment, but also to relate that sentiment to the events and relations out of which it arises (Whyte, 1980). So the actions, mannerisms and emotional responses of informants are crucial to achieving a better understanding of the information which is obtained in the interview situation.

Conducting interviews in the field: the initial steps

Cancer patients were interviewed in their own homes in order to facilitate a relaxing atmosphere in which the informant would feel comfortable and more willing to engage in a conversation. It would also provide an opportunity to establish a rapport with the patients in the context of their own environment. The process of securing the trust of the respondents was probably the most important step in conducting a successful interview. Lee (1993) suggests that disclosure of sensitive or confidential information is usually only possible once trust has been established between the fieldworker and the people being studied. The initial contact that was made with patients in the outpatient clinic helped to establish a degree of trust and understanding.

Deciding on the interview style

There are two basic kinds of qualitative interviews. They can be either in-depth interviews, otherwise known as 'non-directive' methods, or semi-structured interviews. Some authors have asserted that in the strictest sense non-directive interviews are not appropriate for research, since they essentially imply that informants can decide entirely on what they wish to talk about (Whyte, 1980). Others have claimed that since non-directive interviews allow the respondent to dictate the content of the interview, it tends to raise problems concerning the way in which responses can be compared (Burgess, 1980). However, semi-structured interviews allow for a flexible structure where questions are not pre-specified. Instead questions are tailored to the particular respondent and his/her areas of concern.

Another type of qualitative interview is the 'conversation', which has been advocated by Burgess (1980). He claims that the researcher needs to become involved in the lives of the individuals who are studied by means of conversation, in order to elicit moving stories and

provide detailed portraits of interviewees. However, the interviewer may find it difficult to establish a meaningful dialogue with informants who are of a different ethnic background, social class or gender to the researcher.

In this study a semi-structured approach was adopted, where a topic guide was developed to steer the interview in accordance with the original research questions. Subsequently, as interviews progressed, the topic guide began to play a smaller role than it had originally, and the interview often became more of a conversation than an interview. Indeed, the topic guide itself was subject to regular amendments and changes as the interview themes developed.

Asking sensitive questions

Since the task of interviewing cancer patients about their experiences of the disease and treatment was a sensitive process, it became necessary to pay special care to the way that questions were framed at each stage of the interview. As Burgess (1980) suggests, the researcher should be a thoughtful analytic listener who develops the meanings of emerging data throughout the interview whilst formulating insights which will further develop the data. However, the extent to which the interviewer can achieve this will depend on the people he/she is interviewing, as well as on the level of co-operation, which can be secured from his/her informants. More emotive topics were discussed only as the interview progressed and after a good rapport had been established with the interviewee. Whyte (1980) indicates that:

Even though he promises that what people say will remain confidential, there is no reason for believing this assurance from a complete stranger. Therefore, if the interviewer ventures into the touchiest emotional areas at the outset, he finds people responding in a guarded and superficial manner and observes unmistakable signs that they would be happier if he went away and left them alone (p. 113).

Issues concerning emotional matters or of life and death were always initiated by the respondents.

Power in the interview

An important factor that had a significant impact on the interview process in this study was the 'power' relationship between the interviewer and the informant, an issue which warrants some attention. Oakley (1981) argues that women researchers and female interviewees share the same structural position in a male dominated society, which provides them with a shared identification with one another as women. The result is that this promotes a genuine rapport in the interview and leads to 'better' quality data. However, even when the interviewer and the interviewee share the same gender, their race or social class may still preclude them from establishing a good rapport with each other. As Lee (1993) argues, power has a variety of social structural bases and class relations may still operate when there is a shared gender identity. Thus, the power inequalities between the researcher and the researched are often difficult, if not impossible, to eliminate entirely.

The obvious source of inequality between myself and the patients was that I was usually a lot younger. Also, a significant proportion of the interviewees were female. Furthermore, the fact that they were suffering with cancer and I was not, placed them in a vulnerable situation, not least because of the physical as well as mental distress some experienced during the interview. Finally, I was perceived by the patients as a researcher who had a connection with the hospital where they often saw me conducting clinic observations. In order to attempt to reduce the power imbalance between myself and the respondents, I assured them prior to the interview that I was not attached to the hospital in any way, and that I worked as a researcher independently from the hospital. Even though my attachment to the oncology centre gave me a certain degree of legitimacy in the eyes of the patients, it could also potentially have been a source of power inequality too.

In many of the interviews that were conducted social class, gender or racial difference, must have played an important part in the relationship between me and the respondents. However, to argue that one socio-structural factor such as gender played the most significant role would be misleading. The influence of 'personality' differences or similarities is highly underestimated in the social science literature which most frequently focuses on 'role conflicts' between the researcher and the researched (Raudonis, 1992), and on the 'appearance' or 'dress code' of the researcher (Cannon, 1989). I discovered that the exercise of tact, sensitivity, and sympathy proved most fruitful in reducing the power imbalances, which may have existed initially in the interview between myself and the informants.

On the other hand, the idea that the relationship between the researcher and the researched is intrinsically unequal is questionable. There were instances where the power imbalance was not in my favour at all. On most occasions when I went to the respondent's home to conduct the interview, the respondent was already present in comfortable and familiar surroundings, and

usually with another family member in the house. However, as the interview progressed and rapport was established, the inequalities which may have existed between myself and the respondent often disappeared. Lee suggests that there may result a growing closeness between interviewer and interviewee, which can create a blurred line between the role of friend and that of research participant. The close relationship which can result between interviewer and interviewee may lead to problems of 'verification' for the researcher due to his/her close involvement with the informant (Lee, 1993).

'Verification' and the interview process

An important issue, which deserves a mention is the problem of 'verification'. This involves the task of assessing the plausibility of the informant's responses. During the course of conducting interviews, the researcher can take certain precautions in assessing the degree to which the respondent's accounts can be subjected to some kind of process of authentication. During the course of the fieldwork certain factual information was verified with reference to the clinic observations. This proved to be an effective means of assessing how far an interview statement or assertion was true. The observations also helped to test the extent to which patients understood correctly the information which they were given by the oncologists, and this strengthened the validity of the interview data. Some authors agree that things might be reported in an interview in such a way that the interviewer may have no way of knowing what is fact and what is distortion. However, participant observation makes it possible to check such discrepancies (Becker and Geer, 1970).

Another way of testing the authenticity of a respondent's statement is to compare an informant's account with accounts given by other informants. Whyte (1980) points out that the fieldwork often must resemble the courtroom setting in which the researcher's role is to:

...crosscheck the accounts of different informants for discrepancies and try to clear these up by asking for further clarification (p. 116).

In the field, the accounts of informants were often cross-checked with those of other informants to assess the degree of consistency in the responses. If the same phenomenon was frequently reported by different informants then it could be assumed that the reports were likely to be authentic or accurate. I was also given an extra opportunity to test the authenticity of my interview data by re-interviewing the informants on a second occasion, at which time I sought to

re-test some of the hypotheses, which were developed previously. This process helped to ensure that the development of themes was carried out consistently and that there were no discrepancies in informants' responses.

Another possible means of checking the validity of accounts given by informants is to ask questions from different angles. Since some of the concepts and ideas were quite difficult to understand initially, it became necessary to draw on analogies and ask the same questions from different 'angles'. This provided a more complete understanding of the patient's point of view. This idea of asking questions from different perspectives served the purpose of helping to place in context the accounts which the patients provided, which in-turn helped to bridge the gap between *sentiments* and *overt behaviour*. One patient who was extremely optimistic about overcoming her illness, even though she had liver metastases, claimed that she was very hopeful about her recovery. She said:

I feel extremely optimistic...I feel extremely hopeful, people who die are the ones who are hopeless (Interview 16, p. 21).

However, further on in the interview when I returned to the question of hope and asked her if she was this optimistic all the time, she said that her experience of living with cancer was riddled with feelings of guilt and anxiety. This suggested that even when patients claim that they are ready to overcome their disease, they often also reveal that their ability to feel a sense of hope is severely limited by the unpredictable nature of their illness. This is illustrated below (from an interview transcript).

I was very put out by having a headache, it was like a stiffness, and then straight away aah I got tumours flying around, I got tumour on my spine now. And then yesterday morning I had a stiff neck, so now I've got tumours around my neck, which is kind of an exaggerated and hysterical response to a twinge. Now, I don't know how to get out of that.... I hope you make a better PhD in your discipline, I already got one in worrying (Interview 16, p. 21).

There is a need for caution when drawing conclusions from an interview, and there is a need to ask questions in different ways if the interviewer is to achieve a consistent set of responses and an accurate representation of the problem being investigated. The issue of 'validating' the data is one which frequently needs to be addressed by the qualitative researcher, and one which needs to be discussed equally in relation to participant observation methods.

Exiting the field

The main reason why a total of 37 initial interviews were conducted was because the development of new themes had reached 'saturation' point after ten months. However, interviews with the remainder of the 'follow-up' interviewees continued for a period of an additional four months. Nine of the initial interviewees could not be interviewed due to death or poor health. The anticipated high death rate of patients who were initially recruited for an interview was a further reason why the recruitment target was raised. Since a large proportion of the interviewees had a poor prognosis there was a high probability that some may be unable to participate in the follow-up interview. On the whole, the reason why a final number of 37 interviewees was reached is due to a combination of methodological and practical factors. This also indicates the importance of bearing in mind the impact of the study population on recruitment numbers in any research involving cancer.

The analysis of the data was ongoing throughout the study period, and as the observation data reached 'saturation' point more emphasis was placed on analysis and less on 'fieldwork'. Thus, the withdrawal from the Oncology Centre was a gradual process, as sometimes it was important to explore certain themes further once the analysis gathered pace. Therefore, open access to the research setting became important during the analysis stage and the members of staff were happy to allow me to conduct additional observations of consultations. However, as the gradual withdrawal from the Oncology Centre was taking place, some of the follow-up interviews were still being conducted. Thus, the departure from the fieldwork was conducted in two separate phases. The interviews were stopped after approximately ten months as they were no longer aiding the theoretical development of the study. Patients were interviewed on two occasions, and I experienced a level of personal attachment with some people, which made departure quite difficult. Thus, the process of stopping the interviews was more abrupt than the departure from the clinical setting. All the informants who were interviewed were provided with contact details in case they wanted to discuss any further issues relating to their experience of cancer or decision-making, or if they simply wanted to have a chat.

Conclusion

This chapter has provided an overview of some of the difficulties confronting researchers who have chosen to employ qualitative methods with particular reference to methodological issues

encountered in the current study. The chapter described the problems encountered in securing 'physical' and 'social access' and how these problems were overcome, as well as emphasising the importance of addressing the issues of validity and reliability in social research. The need to differentiate between sensitive topics and less sensitive topics is very important in health services research, and one which needs to be addressed if such topics are to be studied effectively. Researching cancer can become emotionally demanding and highly stressful because of the emotive nature of the illness, and the need to adopt the best research methods for the subject under investigation is especially important.

CHAPTER 4

APPROACH TO ANALYSIS

Introduction

Where the analysis of data begins and where it ends is a question that is easily answered by the survey researcher: analysis begins when data collection is completed. In contrast, the task of analysing qualitative data begins as soon as the fieldwork starts. This chapter describes how data analysis was planned and carried out. This is done in some detail in order to make explicit the process of analysis of qualitative data that frequently remains veiled or hidden. Some authors have suggested that a greater emphasis should be placed on the process of analysis and not just the findings themselves (Becker and Geer, 1984).

An important feature of qualitative research is that the analytical task cuts across all stages of the research study. Quantitative research in the social and behavioural sciences tends to adopt a more structured approach in both the collection and analysis of data. The collection and analysis of data is usually treated separately, whereas with qualitative studies, it is very difficult to separate fieldwork from analysis. Nevertheless, this does not mean to say that qualitative research cannot also be carried out systematically. This chapter is divided into two parts. The first illustrates issues encountered in developing a thematic framework whilst conducting the fieldwork, and how the data collection methods influenced the more detailed analysis carried out during the latter stages of the research. The second part of the chapter focuses specifically on the methods, which were used in the systematic analysis of the data, in particular how the interview and observation data were coded, organised and structured. This is followed by a discussion about the problems of inference and proof that were encountered in the research. Finally, the reasons for not adopting other approaches to analysis in the study are provided. In this chapter, I propose to present what Becker (1984) calls, a 'natural history' of the data analysis process.

Combining analysis and fieldwork

Qualitative research is by its very nature an 'inductive' rather than a 'deductive' activity, whereby hypotheses are generated from the data itself rather than formulated prior to data collection. As a result, qualitative research involves generating hypotheses, testing leads, and developing themes, which form the initial steps in data analysis. Since there is no prescriptive method for analysing qualitative data, an assessment of the initial steps to analysis is warranted.

'Interpretation' and 'analysis'

Whether conducting interviews or observations, the process of ascribing meaning to phenomena begins almost immediately. 'Analysis' is a term which can be used or misused, to describe the task of making sense of information by manipulating it in an ordered fashion. However, the process of 'interpretation' of data can be distinguished from the process of data 'analysis'. Interpretation involves simply, the process whereby the meaning of a phenomenon is examined through detailed investigation. Thus, before analysis can be set in motion, the researcher needs to understand contextually what it is that is being analysed. Analysis cannot be conducted properly if the researcher has not built a conceptual model of the wider picture of the phenomenon under investigation. Bruyn (1984) draws a distinction between analysis and synthesis, whereby the researcher cannot conduct an adequate analysis without being able to synthesise or find some unifying structure to the phenomena s/he is studying.

"The tendency of the participant observer is to seek the essence of the life of the observed, to sum up, to find a central unifying principle....The difficulties in synthetic descriptions lay in the tendency to oversimplify (and thereby misunderstand) the nature of the culture. The difficulties of analysis lay in the failure to see the whole, and thereby the significance of the parts" (Bruyn, 1984, p. 316).

As described in the previous chapter, the synthesis of data is tightly linked with the task of familiarising oneself with the culture of the social organisation one is studying. Learning the language of a social group and their daily routines is as important for the analytical process as the more detailed analyses carried out subsequently. Indeed, according to Vidich (1961), the analysis of data is conditioned by the field tactics of the researcher. For instance, the extent to which the

researcher agrees to conform to the norms of the group s/he is studying, or how far s/he can identify with that group, will shape the form that the data will take. The influence of the researcher's role on data quality has been discussed in the previous chapter. Suffice to say that the process of familiarisation with the study group, and the ongoing interpretation of phenomena go hand in hand with the analysis, and neither can easily be carried out in isolation from the other in qualitative research.

Analysing data whilst in the field

During the initial stages of the observation study it was difficult to identify what exactly to observe and what to expect in the oncology clinics, and the first task was to learn how the oncology department operated. From these initial, often sketchy observations, ideas started to emerge which helped to identify a focus for further observations. Observation notes were usually made during the consultations and subsequently written in more detail. Each consultation was described in full, and each new theme was later tested in subsequent observations. This basic principle of developing hypotheses and testing them in subsequent observations continued throughout the fieldwork phase. However, with time the observation study started to adopt a more structured form.

An observation guide was constructed, which consisted of several pointers to guide subsequent observations. According to this guide, acts, activities, meanings, participation, relationships, and settings, became the analytical focus of the observations. The framework which was adopted in this study was flexible, enabling the most common themes to be explored in greater depth through a process of 'theoretical sampling' (Glaser and Strauss, 1967).

As May (1993) claims, observations should be ideally guided by what can be observed at the micro level as well as at the macro level. The need to understand how wider organisational factors affect micro level phenomena and vice versa, is usually a difficult but an important role for the participant observer. In this study it became evident early on, that the nature of the clinician-patient interaction was greatly influenced by 'external' factors such as time constraints. However, in some cases it became difficult to demonstrate through observations, the existence of certain phenomena such as indirect financial pressures on patient care.

Collating evidence from conversations in the consultations between clinicians and patients lent support to certain hypotheses. In addition though, informal conversations with clinicians enabled certain observations to be confirmed or challenged. To this extent, observation does not simply

involve 'watching' the everyday activities of patients and doctors but also talking to them, since some phenomena are more open to direct observation.

Organising data systematically

Observation methods often produce a large volume of descriptive data that contain great detail but little systematic organisation. Becker and Geer (1984) claim that the observer follows no 'design', which means that the data reflect shifting emphases as dictated by new discoveries without pointing towards some pre-defined end. The authors claim that:

"this analysis is often carried on unsystematically, without any consideration of its underlying logical structure or rationale. The observer's hunches and insights are, in fact, truncated and unformalised acts of analysis" (Becker and Geer, 1984, p. 240).

The fact that the researcher often redesigns the focus of the study as he/she develops new insights, suggests that the analytical task is an ongoing one. If the data were written in pure descriptive form, without teasing out analytical insights during the course of the fieldwork, then much of the meaning underlying the data would have been lost in subsequent analyses. Consequently, it was necessary to adopt an interpretative stance when writing up the observation notes in full.

The general framework used to guide the observations and interviews was partly devised from the original research questions, and from the themes that emerged during the fieldwork. Thus, specific types of behaviour or dialogue were placed under the appropriate headings in a coding frame. The coding frame for the observation study consisted of several main headings. After each consultation the observations were written up and coded according to the appropriate categories. However, the observations were not lifted from their original context at this stage. Initially, concepts and indices were selected and defined, following which new revelations and themes were checked for their frequency and distribution in the field. The data collection and analysis process largely took place in parallel, until the main themes reached 'saturation' point where nothing more could be gained by pursuing further observations. The interpretation of interview data consisted of a similar approach, except that themes were refined with constant reference to the interview transcripts.

During the process of refining, examining, and theorising the observation and interview data, it became necessary to refer constantly to previous observations and interviews that had been conducted, as a way of comparing the findings in their wider context. This was important in

assessing how various themes were distributed across all the cases, and also to build on the various theories in order to construct a model based on the research questions. Glaser and Strauss (1967) have referred to this process as the 'constant comparative' method in qualitative data analysis. The 'constant comparative' method was a helpful tool in assessing the usefulness of certain emergent categories within the wider context of the clinic observations and interviews which had already been conducted. For instance, an interesting finding in this study involved the observation that oncologists sometimes used 'persuasive' tactics to influence patients' decisions about treatment. In order to confirm that this phenomenon was in fact occurring in the consultation, the observation notes were provisionally categorised according to particular themes or categories reflecting specific types of behaviour. These codes were then referred to throughout the fieldwork stage and checked for the frequency with which they occurred. Following this, a judgement was made regarding the benefit of pursuing certain themes in more detail on subsequent visits to the clinic. The constant cross-referencing of themes became important throughout the whole course of the fieldwork, as a means of developing concepts, such as 'persuasion'. This aided the development of a robust analytical model.

In addition, the comparative method is a useful analytical tool because it enables the researcher to study the dynamic nature of social behaviour by examining 'change' and 'process'. Glaser and Strauss (1967) support this view as they claim that constant comparison,

"...tends to result in the creation of "developmental" theory. Although this method can also be used to generate static theories, it especially facilitates the generation of theories of process, sequence, and change pertaining to organisations, positions, and social interaction....In comparing incidents, the analyst learns to see his categories in terms of both their internal development and their changing relations to other categories" (Glaser and Strauss, 1967, p. 114).

When referring to the constant comparative method of data analysis the authors are essentially advocating its use in theory development. However, this method is equally fruitful with approaches, which are not necessarily concerned with generating theory. The method can be analytically beneficial for research geared at a more 'practical' level of investigation in addressing specific research questions.

Formulating themes

Whilst in the field, the observer needs to learn ways of mapping out the range of the themes and examining their content. The process of formulating the range of a theme, is conducted provisionally whilst fieldwork is ongoing, and later using a more systematic approach. In this study for instance, careful observation showed that treatment decisions were frequently influenced by the likely benefit of oncological treatment. So, by reviewing the various responses, it was possible to derive a range of perspectives, which allowed for a much more detailed exposition of a theme or a concept. Becker and Geer (1984) also claim that such an approach,

“...adds richness and detail to our description of the perspective’s content by spelling out the particular ways it is seen to operate in actual situations” (Becker and Geer, 1984, p. 246).

For example, in this study the process of mapping the range and nature of clinicians’ responses regarding the benefits of chemotherapy proved to be instrumental in developing a better understanding of the decision making process. Such data was used to draw more specific conclusions about how treatment benefit influenced decision making. For instance, a strong link was identified from the observations between the level of treatment benefit, as communicated by the oncologist to the patient, and the final treatment decision that was reached by the oncologist and/or the patient. Thus, the process of formulating the range and nature of themes proved to be of great importance to the analytic task.

Interviews

All of the approaches to data analysis and interpretation described above relate equally to both observation and interview data. Most of the steps involved in defining concepts and developing the analyses were used for both types of data. However, the interviews with informants were conducted on two separate occasions, during the start of treatment and secondly towards the end of treatment (five months later). In addition, several interviews were carried out with oncologists and nurses, which covered issues relating to organisational factors and their influence on patient care and health care delivery. The interviews with medical staff were conducted in order to explore some of the hypotheses that emerged from the clinic observations relating to treatment

decision making. For instance, the observations showed what happened between clinicians and patients, but not always what the oncologists believed or thought. Thus, the interviews provided another perspective on the data in highlighting the clinician's point of view.

Conducting interviews on two separate occasions served an important function in describing patients' changing attitudes towards their experiences of cancer care and decision making. On many occasions some patients had to discontinue treatment, and the follow up interviews provided an explanation for the termination of treatment which otherwise would not have been obtained. Conducting interviews on two occasions with the same patients allowed for the confirmation or rejection of themes and hypotheses developed previously, and for a more elaborate cross-case analysis of the data. Connections started to emerge between what respondents said previously and what they revealed at the second interview. Both interviews improved the capacity to develop themes to a higher degree of complexity whilst strengthening the validity of the data.

The previous chapter has shown that the process of deriving meaning from an interview involves taking into account the context in which it was conducted, and it presupposes an understanding of the everyday language used by interview participants. However, the development of themes and concepts from the interviews was highly contingent on comparing findings with observation data. For example, Becker and Geer (1984) argue that,

"the process of inference involved in interpreting interviews should always be made explicit and checked, where possible, against what can be discovered through observation" (Becker and Geer, 1984, p. 244).

Such a strategy aims to strengthen the internal validity of the data and helps to provide a clearer insight of the problem being studied.

Post-fieldwork analysis

The following sections illustrate how data analysis was conducted following the completion of the fieldwork. In particular, the methods used to build conceptual models from the data and the ways in which causal analyses were conducted are described.

Coding method

Throughout the data collection phase, assigning codes to themes was a regular feature of the analytic task. This proved to be extremely useful in the development of subsequent ideas and their examination and re-examination in the field, as well as in setting up a more systematic framework for future analysis. Strauss (1987) claims that coding assists in the generation of questions. He claims that coding fractures the data and allows interpretation to higher levels of abstraction, and it is the primary operation for developing core categories.

Coding the data

Following the fieldwork, the observation notes and interview transcripts were carefully coded using a coding frame, which was developed during the course of the fieldwork. The coding frame consisted of several 'core' categories and sub-categories which reflected the themes and concepts which were derived from the observations and interviews. Subsequently, all the coded excerpts from the field notes were grouped together according to their respective categories and sub-categories on a word processor. It was paramount that the coded text was not lifted out of its immediate context, so as not to lose any meaning. For example, the category that was labelled "communication style" included the text from all the observation notes which related to this category. This categorisation is referred to as 'selective' coding by Strauss (1987) whereby,

"... the researcher has decided which categories are central to the research project. When they are decided upon, however, then the researcher moves into selective coding, when all other subordinate categories and subcategories become systematically linked with the core" (Strauss, 1987, p. 69).

Having grouped all the evidence relating to the core categories systematically, the next step was to utilise this coded information in a way which was meaningful and not devoid of its context. Thus, the next step was to define the concepts, map out the range of phenomena, find associations, and produce causal networks.

Identifying concepts and trends in the data

Having completed the coding, the next task of the analysis involved familiarising oneself with the data. This involved reading and re-reading the interview transcripts and observation notes, and searching for general patterns and linkages within the coded categories. This process was applied to the interview data and observation data in exactly the same way. Ritchie and Spencer (1994) suggest that once the data is coded it needs to be rearranged in order to build up a picture of the data as a whole. This is sometimes referred to as 'charting'. This process involved listing all the cases in a grid and identifying certain trends and themes that were considered to be of significance during data collection. Comparisons were then made between the different cases that were examined according to the appropriate thematic reference. For this study, the data were arranged and summarised according to how patients understood the treatment decision that was made. These different interview responses were examined and contrasted with each other. This led to further insights specific to the themes being examined. The charting process was therefore a useful way of describing the range of responses and their relevance to a particular theme.

Charting the interview data enabled a thorough examination of how patients perceived the benefits of oncological treatment. This led to a detailed definition of the concept of 'treatment benefit', which emphasised the extent to which the patients' perceptions of treatment benefit differed from the 'official' definition used by the oncologists. The data were constantly interpreted within the context of the interview transcript or observation notes to avoid divorcing it from the original context.

Another method that was used to define more clearly some of the key dimensions of a theme, was to map out the 'range' and 'nature' of phenomena as suggested by Ritchie and Spencer (1994). The observation data indicated that many patients were 'encouraged' by their oncologist to accept certain treatments or reject them. The process of 'mapping' the range of reasons why doctors 'persuaded' patients to accept or reject treatment, provided a more intricate and detailed understanding of decision-making behaviour. The identification of the concept of 'justification' provided a clear understanding of not just why clinicians wanted patients to follow their advice, but also how they went about this task. A similar process of charting and mapping the data was carried out for both observation and interview data.

Identifying associations

Qualitative data analysis has been seen to be more adept at developing themes and concepts, but less useful in its ability to develop causal relationships. However, Miles and Huberman (1994) have argued to the contrary, that since qualitative research can generate data of a greater depth and relational complexity, the causal links between and within phenomena can be traced more intricately than in quantitative analysis. For instance, the authors argue that,

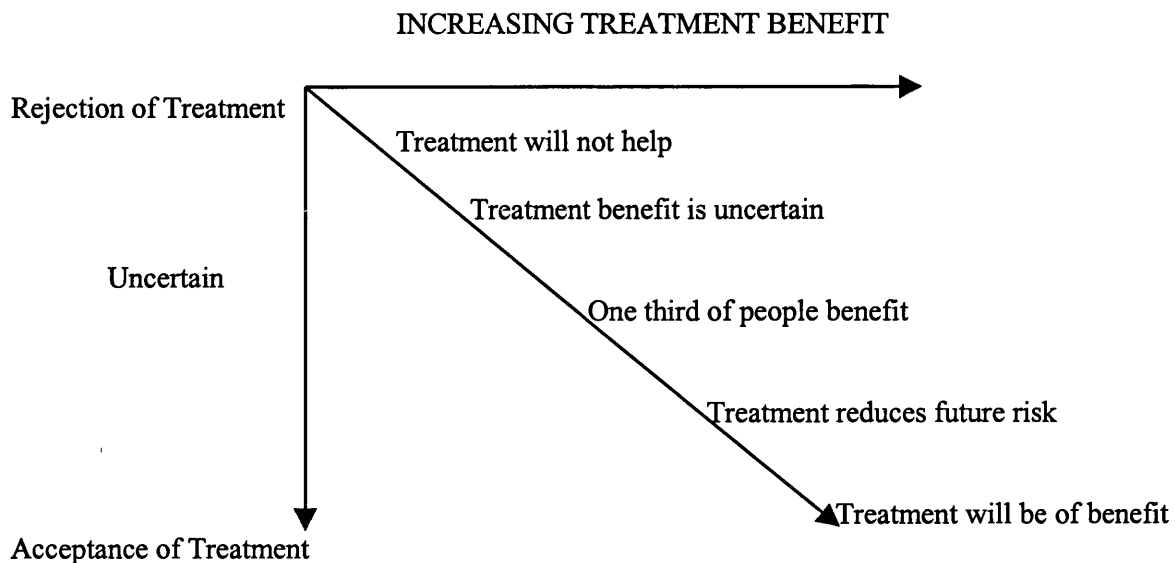
“the conventional view is that qualitative studies are only good for exploratory forays, for developing hypotheses and that strong explanations, including causal attributions, can be derived through quantitative studies...We consider this mistaken. We don't understand how or why something happened, and can only guess at the mechanisms involved” (Miles and Huberman, 1994, p. 275).

Qualitative data analysis has several potential advantages to quantitative data. It can provide a more detailed insight into the mechanisms at work in a certain situation. It can achieve this as it intrinsically deals with phenomena at a local level. Also, qualitative data analysis can provide an effective illustration of the temporal dimension of phenomena, by identifying the connections between variables over time.

So far, the analysis process was limited to identifying important themes in the data, as well as defining their underlying properties and mapping out the range of phenomena. However, the next level of analysis focused more selectively on identifying associations and causal relationships in the data. This task proved to be the most challenging and required a good familiarity with the data. The analysis of the observation data involved a slightly different approach to the analysis of the interview data, since the two respective methods produced information of a qualitatively different nature. For instance, the observation notes mostly focused on ‘behaviour’, and the interviews generated data which focused on ‘views’ and ‘perceptions’.

The first step in the analysis involved the creation of typologies from the themes. Figure 1 illustrates the relationship between the communication of ‘treatment benefit’ by the clinician and the final treatment decision that was reached.

Figure 1: *The effect of treatment 'benefit' on decision reached*



This diagram shows that as the benefit of treatment increased, the more likely it was that the patient would accept treatment, and when the benefit of treatment was smaller then the patient was more likely to reject the treatment option. However, when treatment benefit was communicated in 'uncertain' terms then the patient was unlikely to make an immediate decision, and became more uncertain about the likely benefit of treatment. The observation data as well as the interviews strongly suggested that patients' perceptions of treatment benefit were strongly associated with the consultant's communication style. The typology can also be used to make predictions. For instance, by examining figure 1 it is evident that patients were more likely to undergo chemotherapy treatment when the benefit was most clear, and they were least likely to have treatment when benefit was least clear. However, the 'grey' area in between suggests that where benefit is uncertain, treatment decisions cannot be easily predicted.

During the course of charting observation and interview data a number of connections were made between variables, and the next task was to plot some of these associations. The method used to plot associations was similar to that advocated by Ritchie and Spencer (1994) who composed a matrix of responses to a central theme from all cases in order to identify certain trends. In the current study, respondents were grouped into two 'categories': those who were given 'curative' or 'palliative' chemotherapy. After formulating a matrix, it became evident that particular groups of respondents interpreted their involvement in decision making in quite different ways. Patients who were in the adjuvant chemotherapy group felt they had a greater level of control in determining the final treatment decision than patients who were more seriously

ill and therefore offered palliative chemotherapy. 'Palliative' patients felt that they were compelled to follow the clinician's advice. This example illustrates an important way in which attitudes and behaviour can be checked systematically for associations, using both interview and observation data. This process of mapping associations between variables is a useful means of understanding the way that they are connected to one another. However, once certain connections have been established within and between themes and concepts, the next step is to trace the logical path of an association or the mechanisms involved, in order to obtain a more clear causal patterning of the data. Miles and Huberman (1994) advocate the use of 'sequencing' the data or plotting variables according to a causal 'chain analysis' (p. 227).

Using matrices to analyse data

The analysis undertaken in this study involved showing associations between themes and variables and how they fit in the wider causal model or network. Miles and Huberman (1994) refer to this process as a 'variable by variable matrix', which has two main variables in its rows and columns, and specific indicators of each variable are ordered by intensity. The cell entries, rather than being extracts of data, are case names. So we can see which cases have included a specific type of interaction of two main variables.

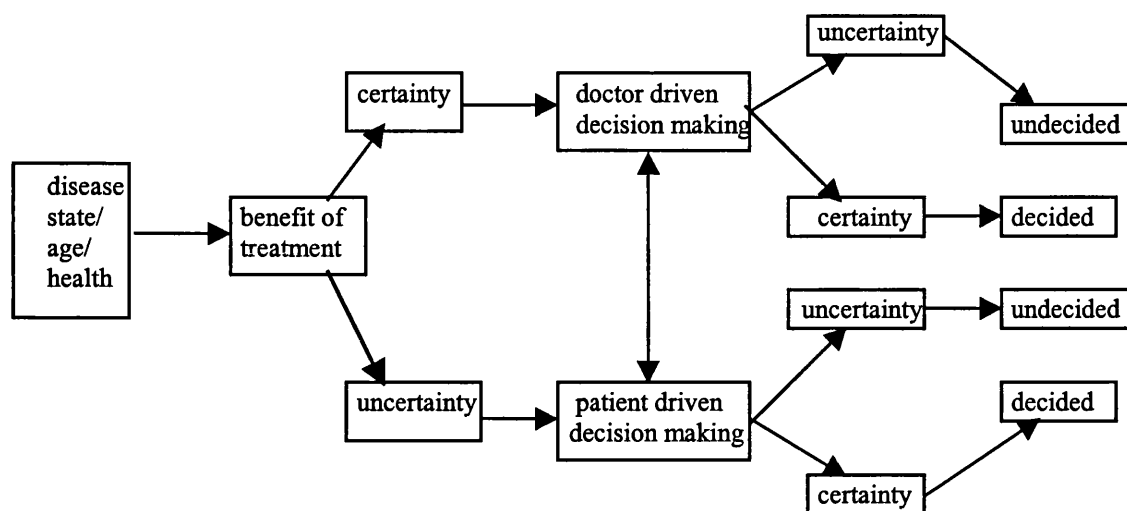
Some of the analysis was conducted using matrices similar to that described above, as a means of drawing relationships between data and establishing associations between themes. For example, I wanted to assess whether respondents accepted or rejected chemotherapy treatment based on their perception of the seriousness of their disease. The matrix in appendix 6 illustrates how the two variables were represented using a matrix. The first two columns provide the reasons why respondents accepted and refused treatment. The next seven columns were broadly divided progressively according to the 'seriousness' of the illness as perceived by the respondents, ranging from 'less serious illness' to 'serious illness'. The matrix in appendix 6 leads to the conclusion that respondents who felt their disease was 'serious', accepted treatment because they felt that something could be done about their illness. Hence, many of the reasons for accepting treatment in the 'definition' column suggest that the disease could be overcome. For example, 'treatment may prevent spread' and 'extend life' (See appendix 6). However, of those respondents who perceived themselves as having a 'serious' illness, most believed that treatment would not have much impact on the course of their illness. Hence, many patients felt that their 'cancer was too advanced' or 'the doctor would not advise treatment'. Thus the main difference

between those who accepted and those who rejected treatment, was their perception of the likely benefit of oncological treatment and their perception of their illness.

‘Sequencing’ the data

Strauss (1987) refers to the importance of building ‘integrative’ diagrams during the data collection phase right through to the final stages of analysis. Consequently, a wider analytical picture is constructed using a ‘map’ of the important findings emerging from the research. Since the data were disorganised and fragmented during the earlier stages of analysis, the process of constructing integrative diagrams helped to give the data some underlying structure and direction. Integrative diagrams were also important in selecting foci for further theory development and investigation. Having completed the data collection, the need to produce diagrams of variables, and to show how they related to the wider theoretical model, was central to the analysis. One way that variables were linked together was by means of sketching causal diagrams. Some authors have referred to this as ‘sequencing’, which is a particular strategy for linking variables in an effort to trace their line of causality and association (Strauss, 1987; Miles and Huberman, 1994). The use of multiple research methods can help to construct a very elaborate model of the causal mechanisms that exist between and within variables. Figure 2 below is a simple illustration of a causal sequence which was devised from the observation data and which guided subsequent analyses.

Figure 2: *Nature of decision-making under conditions of uncertainty*



The diagram provided above was used to show the basic processes which influenced decision-making behaviour between the oncologist and the patient. It shows that the oncologist explained the benefit of treatment to a patient based on specific criteria, such as the disease-stage, age, and general health status of a patient. Whether it was communicated as being of benefit or of uncertain benefit influenced the decision-making behaviour of the doctor and the patient. Where treatment was communicated as beneficial, the patient usually felt a high level of ‘certainty’ about the most appropriate course of action, and the rest of the decision making behaviour was left to the oncologist. However, if the patient regarded the treatment to be of ‘uncertain’ benefit, the patient often played a greater role in decision making.

Such sequences as the one illustrated here help to bring concepts together and make causal connections between them. Integrating such diagrams into the general explanatory model was the main task of analysis during this study. During the fieldwork such models were constructed and modified, and comparisons were made between the interview and the observation data. However, the difficulty was to construct many ‘integrative’ diagrams that logically followed on from one another, rather than conduct separate analyses, which had no connections with previous analyses and interpretations. Strauss (1987) explains this.

“There should not be an aggregate of multiple diagrams but successive ones. Each later one should incorporate elements of earlier ones; or alternatively, the larger, more summarising diagrams should encompass most of what is sketched in the earlier diagrams. In short the diagrams should cumulate in snowball fashion” (Strauss, 1987, p. 278).

Although the initial objectives of this research study were not primarily concerned with identifying causal chains between ‘bits’ of data or variables, the process of examining causal networks helped to connect variables and identify patterns which otherwise would not have been found. The research study aimed to examine how treatment decision-making was carried out, what influenced decision making behaviour, and what were the patient’s views regarding this process. Certainly, these questions could not be simply answered by adopting a controlled ‘cause’ and ‘effect’ approach to the analysis. As Bruyn (1984) argues, qualitative analysis need not be cast in a deterministic framework. Decision-making behaviour cannot always be reduced to simple, or indeed complex, models of causality, which can be tested to derive precise conclusions. Qualitative analysis is a ‘process’, which can identify plausible or likely connections between ‘pieces’ of data that are supported by the evidence. So, although the examples presented above sought to provide an overview of how the analysis was carried out, they also demonstrated that the process of generating and conceptualising the data was also a subjective process (Bruyn, 1984). Thus, the analysis is undoubtedly shaped to some extent by what the analyst considers to be of value.

Analysing interview and observation data together

The credibility of the research hinges on the role of the researcher in the field. The issue of data credibility is made more explicit, however, when using multiple methods of data collection, since greater effort is needed to ensure that the data is ‘reliable’. Vidich (1961) claims that,

“the social positions of the observer and the observed and the relationship between them at the time must be taken into account when the data are interpreted” (Vidich, 1961, p. 172) .

As with all interview data, the findings usually reflect peoples’ perceptions and views about a certain issue. However, this does not mean to say that just because an association or cause has been found to exist between two variables, then it is likely to reflect reality accurately. Such a conclusion cannot be simply based on what people say. In order to verify assertions made by respondents it is important to obtain data from other sources. What people say, should ideally be supported with evidence of what they actually do (Becker and Geer, 1970).

As mentioned in the previous section, analysis should be an ‘integrative’ process whereby separate analyses combine to develop an understanding of the complete model of the subject

under investigation. The advantages and disadvantages of adopting multiple methods in qualitative research have been discussed in some depth in the previous chapter. However, the problem which had to be resolved in this study was how to synthesise both interview and observation data. Interviews and clinic observations were conducted contemporaneously. Indeed, interviewees were recruited from the setting where observations were carried out. Further, since the research aims focused primarily on how decisions were made between oncologists and patients in the clinic, it made sense to develop analytical 'links' between both research methods during the data collection phase of the study. This was achieved by making comparisons between what the study respondents revealed during the interview and what in fact happened in the clinic. Therefore, themes were developed in parallel from both 'data sources'. The themes that emerged from the clinic observations were explored during interviews with patients. Likewise, what was revealed in the interviews was often explored in the clinic. Becker and Geer (1970) have also stated that the use of multiple methods in qualitative research not only strengthens data credibility, but facilitates a better understanding of the phenomena under investigation. They claim that participant observation in combination with in depth interviews,

"...provides a rich experiential context which causes the researcher to become aware of incongruous or unexplained facts, makes the researcher sensitive to their possible implications and connections with other observed facts, and pushes him/her continually to revise and adapt his/her theoretical orientation and specific problems in the direction of greater relevance to the phenomenon under study" (Becker and Geer, 1984, p. 141).

Having developed themes and connections between observation and interview data in the field, it became necessary to formulate more detailed connections between the data once fieldwork was completed. For example, the interviews indicated that most patients experienced little involvement in decision making, and that the clinicians often recommended the best treatment options to the patients. However, the observational study revealed that some of the same patients played an 'active' part in the decision-making process and the clinician usually had to 'justify' why a certain decision was recommended. The consultations were not dominated by the doctor as patients often made decisions which contradicted the clinician's advice. This suggests that the use of observations and interviews helped to elaborate and explain more fully the data. Also, the use of multiple methods can help to improve the explanatory potential of a research study whereby one method can reveal information that cannot be obtained using a different method. For instance, although most patients claimed that the oncologist provided a 'neutral' summary of the information, it was evident from the analysis of the observation data that many oncologists tailored the information according to whether they preferred a patient to accept or reject

treatment. Thus, the observations helped to clarify some of the findings obtained from the interviews. Similarly, the interviews provided a better means of establishing the reasons for the decisions that were made by patients, and the observations provided an overview of the context within which decisions were made. Becker and Geer (1984) state that multiple research methods strengthen the analytical rigour of the findings.

"We add to the accuracy of our data when we substitute observable fact for inference. More important, we open the way for the discovery of new hypotheses for the fact we observe may not be the fact we expected to observe. When this happens we face a new problem requiring new hypothetical explanations which can then be further tested in the field....The difficulties in analysing change and process on the basis of interview material are particularly important because it is precisely in discussing changes in themselves and their surroundings that interviewees are least likely or able to give an accurate account of events" (Becker and Geer, 1984, p. 140).

The authors indicate that when employing multiple research methods the process of deriving conclusions from the data alters. This is because logical inference is replaced by empirical evidence, and this serves to strengthen the credibility of the findings.

Assessing data credibility

This section will expand on some of the ways in which problems of inference and proof were resolved. The task of strengthening data credibility takes place during the fieldwork to a large extent. Becker (1984) stated that the analytical process involves four stages.

The selection and definition of problems, concepts, and indices; the check on the frequency and distribution of phenomena; and the incorporation of individual findings into a model of the organisation under study. The fourth stage of final analysis involves problems of presentation of evidence and proof (p. 23).

Many readers of qualitative research reports complain about the lack of effort in explaining the operations by which the evidence has been assessed. This section aims to show how the findings were subjected to checks of validity (Becker, 1984).

Representativeness of the data

Most checks of validity and credibility take place during the fieldwork in qualitative research, since it is only then that the researcher is in the position to check and re-check the data. After the fieldwork is complete little can be done to iron out inconsistencies or weaknesses in the data. One way of strengthening the validity of the data whilst in the field, is to check the distribution and frequency of phenomena. Becker (1984) claims that,

"The observer, possessing many provisional problems, concepts and indicators, now wishes to know which of these are worth pursuing as major foci of his study. He does this, in part, by discovering if the events that prompted their development are typical and widespread.... just as he is more convinced if he has many items of evidence than if he has a few, so he is more convinced of a conclusion's validity if he has many kinds of evidence" (Becker, 1984, p. 194).

When conducting interviews and clinic observations, many insights and themes were tested and re-tested across different cases to assess the distribution of phenomena. For instance, during the interviews it was hypothesised that a patient's trust in the oncologist would be affected by the volume of treatment related information that he or she received. This hypothesis was then tested during the interviews.

The issue of 'representativeness' of the data is a problem that some qualitative researchers have abused in the past for more political or ulterior motives. For instance, Bury (1997) has suggested, with reference to Ann Oakley's study on childbirth (1980), that some researchers make claims which are not representative of the group of people they are studying. Oakley found that the women who she studied expressed nothing but satisfaction with their hospital care during childbirth, however, the author reconciled this finding with her more critical opinion that,

"At the moment, it is not possible to produce research findings that show that the majority of women are dissatisfied with medical styles of childbirth management-in the sense of wanting a radically different alternative to medicalised birth. But, on the other hand, many studies, including this one, do demonstrate a great deal of discontent" (Oakley, cited in Bury, 1997, p. 91).

This could be viewed as too bold a statement bearing in mind that the data did not support her feelings about the medical profession's repression of women and the medicalisation of childbirth.

This example demonstrates the dangers of drawing conclusions from data that are not representative of the wider group under investigation.

Becker (1984) advocates a method whereby the research problem needs to be related to a larger social context as a means of strengthening the validity of the data. So in this study the findings were related to the wider issues which may be influencing treatment decision-making practices, such as the financial pressures and organisational factors. Conducting interviews with members of staff helped to confirm or disprove some of these hypotheses.

A further means of improving the representativeness of the data is to 'replicate' a finding (Miles and Huberman; 1994). For instance, the process of testing a hypothesis during interviews or consultations involved conducting repeated observations and interviews with informants. This process continued until there was adequate evidence to confirm a finding or refute it.

Searching for 'negative cases'

Since statistical tests of significance, which are applicable in quantitative research, cannot be applied to qualitative data, it is necessary to adopt different strategies with which to assess the truth of a proposition. One strategy that was used in this research study involved searching for 'negative cases' or phenomena, which opposed the general model (Miles and Huberman, 1994). As qualitative research usually involves repetitive observation and careful refinement of emergent themes, the frequency of 'negative cases' is usually quite small. Also, the method of theory building by its very nature tends to reduce the proportion of 'negative cases' that can be detected in a specific model or proposition. For example, the clinic observations tended to reveal that under certain conditions some oncologists gave 'conflicting' messages to patients. It was also true that many patients did not receive conflicting information from oncologists. Having refined this idea through further observations, it became clear that this phenomenon only happened when the oncologist failed to ask the patient what they were previously told by their surgeon. Thus, conflicting messages were communicated to patients in situations where the oncologist had not listened to the way the patients perceived their illness and what they were told by their surgeon on a previous occasion. Subsequent observations were conducted to check whether these conditions were supported by further evidence. By refining a theme, the number of negative cases was drastically reduced. This process also contributed a great amount of detail to particular themes by demonstrating the conditions under which it exists.

Weighting the evidence

It was evident during the fieldwork that data from some informants was more 'reliable' than data from others. Some authors have suggested that some informants,

"...may be knowledgeable, close to the event, action, process, or setting with which you're concerned" (Miles and Huberman, 1994, p. 268).

For instance, it would be more appropriate to attach greater weight to the responses given by clinicians about clinical matters than patients. Similarly, more weight was attached to the observations than the interview data, when attempting to answer questions relating to 'process' and change.

Sometimes too much weight can be attributed to the subjects under investigation (Bruyn, 1984). For instance, problems of over 'rapport' with informants, and the tendency of some researchers to romanticise the plight of their study subjects, can undermine the interpretative value or validity of the data. The main reasons why interviews were conducted with cancer patients, as well as with medical staff, had been to avoid this problem. A more 'balanced' objectivity was the aim of employing different multiple methods, which sought to avoid what Bourdieu (1992) called the 'official native accounts'. He stated that,

"...the point of view of the detached sociological observer-looking for explanations-produces a distorted understanding of the situation in question, a view which reifies and overemphasises ideals, norms, values etc. These become represented as the rules which govern or determine social action" (Bourdieu cited in Jenkins 1992, p. 48).

There is a tendency for social scientists to attach too much theoretical importance to certain phenomena. What is recommended is an approach that advocates a greater focus on the researcher's subjectivity, as well as his/her relationship to the subjects being studied. Hence a more 'reflexive' approach to social investigation. In other words, the analyst should adopt a self-reflecting strategy to the analysis of data whereby his or her impact on the researched is taken into account, thus enhancing the credibility of the data.

A further approach to weighting the evidence in this study involved showing the findings to informants as a means of assessing the plausibility of certain hypotheses. Certain authors have warned against using validation strategies that involve dependence on informants' statements as a means of confirming certain findings. According to Whyte (1980), such strategies often

underestimate the problems involved in relying entirely on confirmation by informants. However, the follow up interviews helped to 'test' some of the hypotheses that were developed. For example, the first line interviews were used to develop a general model of the influence of 'information provision' on the concept of 'trust'. Consequently, the hypothesis emerged that the more information patients received from the oncologist, the more likely they were to invest trust in him or her. However, the follow up interviews revealed that this hypothesis was not entirely complete. Information yielded by those subsequent interviews indicated that the disclosure of information did not by itself affect the patient's trust in the doctor. Rather, other qualities such as 'honesty' on the part of the clinician, were equally important. Thus, various hypotheses were tested with the same respondents on different occasions with the aim of strengthening the validity of the data.

Adopting a systematic approach to analysis

As indicated earlier, the process of qualitative data analysis is seldom as clear-cut and tightly structured as the analysis of quantitative data. The process of qualitative data analysis requires the development of 'structure' in the data during the course of the fieldwork and subsequently. With quantitative analysis, the form the data take is predetermined prior to fieldwork, and the analysis process commonly involves the selection of several variables for statistical 'processing'. Thus, the analysis frequently involves the use of a single method of analysis. In contrast, qualitative data analysis inherently involves the use of multiple approaches as the analytical project is ongoing and 'evolutionary' in nature.

'Grounded theory'

The methodological approach used in the analysis and data collection was broadly based on the 'grounded theory' method advocated by Strauss and Corbin (1997). In this section I will provide a description of the way that theory development proceeded in the study, and then briefly examine two limitations of using the grounded theory method as proposed by Glaser and Strauss (1967): – 1) the issue of 'objectivity' and 2) the issue of research relevance. Grounded theory was used in this study although not in the 'objectivist' way originally proposed by Glaser and Strauss

(1967). The approach that was adopted was based on the assumption that total 'objectivity' cannot be attained because the researcher's personal views and pre-existing knowledge will (and should) affect the process of interpretation and analysis.

Using grounded theory in the current study

The grounded theory method proposes a 'bottom-up' approach to the generation of data, whereby the themes are grounded in the data that is collected. In the current study themes and hypotheses were generated throughout the duration of the fieldwork, and subsequently tested and re-tested. Recurrent themes were subjected to closer scrutiny in subsequent interviews and observations until the theory development process reached 'saturation' point when a theme or a concept could not be developed further. The interview process during the current study was non-directive as far as possible, and one where informants were probed continuously to clarify issues that were raised and emergent themes were contrasted with different informants to examine their salience and relevance to the topic under investigation. Similarly, themes were generated from repeated observations of oncologist-patient interactions. During each observation the dialogue between the doctor and the patient was recorded verbatim, and detailed notes were made following each interview describing the nature of decision-making, the style of interaction, and the manner of the participants. The constant comparative method was used whereby the data were explored for salient themes throughout the duration of the fieldwork. Theoretical comparisons were then made between the different observations in order to identify common trends and patterns in the data (Glaser and Strauss, 1967). Theoretical notes were made throughout the study in search of emergent categories, which helped in the theory formulation task. Indeed, the themes emerging from the interviews were used to explore similar issues in subsequent observations (and vice-versa). This way, both methods generated evidence relating to the topic under investigation, which helped to strengthen the validity of the data.

During the early stages of the fieldwork the interviews and observations provided a focus for exploring various themes which were broadly related to the initial aims of the study. The study then began to narrow down on more detailed issues relating to the treatment decision-making process, such as how the informants themselves defined 'decision-making'. These issues were tested and re-tested in subsequent observations and interviews, and their relevance and importance to the themes in question were assessed. Once further observations and interviews could no longer add to the theory development process, data collection was said to have reached 'saturation' point and the focus of the study turned to another related theme. When new themes of

particular relevance to the study aims could not be identified anymore further fieldwork was ended. The analysis of the data and the fieldwork were conducted concurrently so that the meaning of the data was not lost and each theme was explored fully. Each theme was analysed within the context of the entire interview and consultation, so that the views of the informants could be traced back to the initial consultation with the oncologist. This way their views regarding decision-making were placed within the context of their consultation and the theory development task became more rigorous.

Theory development and ‘objectivity’

The previous section describes the way that grounded theory was utilised in the current study. The interview and observation data were analysed using the constant comparison technique as described above (Glaser and Strauss, 1967). However, in certain respects the approach to analysis that was adopted in this study departed from the grounded theory method as originally proposed by Glaser and Strauss (1967).

Glaser and Strauss suggest that the researcher should be as objective as possible to ensure that his or her subjective views do not bias the data, and that the theory is grounded only in the data and not distorted by other sources including the researcher’s personal views. They present grounded theory as an objectivist method that relies upon the assumption that there is an undistorted reality which can be understood in its ‘pure’ form. However, the ability to be completely objective during fieldwork is difficult, especially if investigating an emotive topic. Moreover, it may not always be ethically sound or desirable to maintain a distance from an informant, as it could prevent establishing a good rapport, which could in turn jeopardise the quality of the data. Thus, some level of researcher involvement can sometimes strengthen data quality. However, a degree of detachment from the subject matter can also be useful in helping the researcher to cast a more critical eye on the data. Thus, a balance often needs to be struck between ‘objectivity’ and the extent to which other ideas, theories, and practical concerns can be allowed to influence the theory development process during the fieldwork and analysis.

More recently, grounded theory has been increasingly viewed as a process that cannot easily detach itself from the influence of subjectivity. Strauss (1987) identifies the researcher as being actively involved in the generation of theory rather than excluded from the process. Strauss and Corbin (1997) suggest that researchers using grounded theory should draw on their experiential knowledge to collect data and also recognise that they are an important ‘interactant’ in the research process. They also state that a substantive theory that emerges from grounded theory

research should provide a framework for action with a necessary practical application (Strauss and Corbin, 1997). This is important so that the aim of research can be tailored to the 'discovery' of new theories whilst showing a practical relevance. Entering the field with a 'clear book' as Glaser and Strauss (1967) advocate was not always possible and analytically undesirable. Theory development was grounded in the data, although, it was also influenced by pre-existing ideas and research findings. The theory development task benefited from pre-existing research ideas and leads generated from other studies, which helped to drive the process forward. This way important questions that were previously raised by other research were explored rather than ignored during the fieldwork.

Practical relevance

Hammersley (1992) argues that social science has no value if its findings are not relevant to people outside of the research community. He identifies three factors by which relevance might be judged: the importance of the topic, the contribution of the literature, and improvement to practice. Indeed, the question of relevance has been raised by some sociologists in relation to the sociology of emotions, where they claimed that if research has not shown to have an impact on practice then its relevance is in question (James and Gabe, 1996).

In this study, a broad research question was defined at the outset, which generally aimed to explore the nature of treatment decision-making in colorectal cancer. Even though data collection involved searching for new and recurrent themes, the broad aim of the study was to investigate the nature of decision-making in oncology. Leaving the data to 'guide' theoretical development, as Glaser and Strauss (1967) propose, would not have been appropriate in this study where the intention had always been to explore the nature and process of 'decision-making. This does not mean that an 'objective' approach was not adopted in the analysis. However, the exercise of 'total' objectivity without due consideration to the potential benefit and relevance of pre-existing research findings and theories could have led to an under analysis of the data. Indeed, crucial insights might have been missed if too narrow a conception of the social and its influences had been adopted. Incorporating broad research questions at the outset provided a relevant focus to drive the analysis forward, rather than presenting an obstacle to that analysis. For instance, previous research has largely neglected the role of the clinician in decision-making, and this study aimed to explore how far the doctor does in fact influence the decision-making process through observations of doctor-patient interactions. If the current literature on decision-making had not been examined prior to, and during, the fieldwork then the relevance of this important question

may not have been considered in the analysis or the study design. Instead, the process of theory development might have focused only on patients' perceptions of decision-making and less on the clinician's role. For this reason it was important to proceed with the data collection by investigating the broad issue of treatment decision-making, rather than simply adopting an objectivist stance and exploring themes which arise from the data with no reference to their practical as well as analytical importance.

Conclusion

This chapter illustrates the approach to analysis adopted in this study. The main objective was to describe how the process of collecting data shaped the analytic endeavour, and also how it influenced the nature that the data took subsequently. The chapter has demonstrated how the formulation of themes and concepts during the fieldwork, was not just an essential element of the analysis, but also predetermined the type of analysis that could be carried out subsequently. The chapter also described the various approaches to analysis that were adopted following the completion of the fieldwork, and how they were optimised so as to utilise the data most effectively. However, the main impetus of the chapter was to show how a systematic and a structured approach to the analysis of qualitative data could be achieved successfully. The need to assess the credibility of the data and check the validity of conclusions, is an integral part of the analytic task. Therefore, I have shown the importance of analysing and validating the data simultaneously. Finally, I have explained the rationale for using the methods of analysis employed for this particular study, and how the grounded theory method was utilised.

CHAPTER 5

CHARACTERISTICS OF THE STUDY POPULATION

Introduction

This chapter will present the characteristics of the study population and show from where the sample has been drawn. The first part of the chapter will provide a general description of colorectal cancer in the UK population, followed by a description of cases of colon and rectal cancer in the South West Region and in Avon. The second part of the chapter will describe the population of new colorectal cancer patient presentations to the Bristol Oncology Centre, and the process through which the resulting study population was finally achieved. The chapter also shows the proportion of patients who were observed during clinics, the numbers of patients who were approached for an interview and the proportion who finally agreed to participate. Finally, a more detailed description of the characteristics of those patients who participated in the interviews will be provided, and the attrition rate due to withdrawal and death.

The data for the incidence rates of colorectal cancer in the UK population, the South West region and in Avon, were provided by the South and West Cancer Intelligence Unit. The annual rates of new presentations to the Bristol Oncology Centre were retrieved from the MDI registration database at Bristol Oncology Centre.

Sampling stages

The incidence rates for colon and rectal cancer in the UK population are missing for the years following 1992 because there is an absence of complete data from cancer registries. Consequently the information in this section has been limited to 1992. Also, the South and West Cancer Intelligence Unit was not able to supply complete estimates of the incidence of colorectal cancer

classified by stage at diagnosis. Information will be limited to a description of incidence rates for colorectal cancer by site, sex, and age.

Table 1 indicates the incidence rates for colon and rectal cancer in England and Wales in 1992. According to table 1, men are generally more likely to be diagnosed with colon and rectal cancer than women. This trend is supported by the age standardised incidence rates for men and women with colon cancer which are 30.3 and 24.3 per 100,000 of the population respectively. Similarly, rates for men and women with rectal cancer are 22.8 and 12.3 per 100,000 of the population respectively. Also, the rate of colon and rectal cancer for both men and women increases progressively with age. The incidence rate of colon cancer among men and women between the ages of 50 and 54 is 25.7 and 21.2 per 100,000 of the population respectively. However, the incidence rate of colon cancer for men and women between the ages of 75 and 79 is 245.1 and 168.7 per 100,000 of the population respectively. This suggests that the incidence rate of colon cancer increases more rapidly with older age. A similar pattern can be seen in the incidence of rectal cancer, where men have a higher rate than women in all age groups, and the incidence increases progressively with advancing age. Table 1 also shows that the incidence rate of rectal cancer tends to be lower than for colon cancer in both sexes, and for all age groups in 1992.

*Table 1: * New registrations of colorectal cancer in England and Wales (1992)
per 100,000 of the population*

<u>Age specific</u>	Colon		Rectum		
<u>incidence rates</u>	Ageband	female	male	female	male
	0-4				
	5-9				
	10-14				
	15-19		0.1	0.1	
	20-24	0.2	0.3		0.2
	25-29	0.7	0.4		0.5
	30-34	1.0	1.0	0.8	1.1
	35-39	2.7	2.9	1.7	2.1
	40-44	6.4	6.7	4.3	5.1
	45-49	12.0	10.3	6.7	12.1
	50-54	21.2	25.7	13.1	24.1
	55-59	37.2	44.0	22.4	39.5
	60-64	65.6	78.3	32.4	63.1
	65-69	95.6	120.9	46.5	94.3
	70-74	121.5	154.1	59.8	121.3
	75-79	168.7	245.1	86.4	157.1
	80-84	226.4	280.5	95.9	174.2
	85+	256.1	324.4	109.7	176.3

<u>Age</u>	95% ucl	24.8	30.9	12.7	23.3
<u>standardised</u>	ASR	24.3	30.3	12.3	22.8
<u>incidence rates</u>	95% lcl	23.8	29.6	11.9	22.2
	s.e.	0.3	0.3	0.2	0.3

* South and West Cancer Intelligence Unit (1998)

Table 2: New registrations of females with colon cancer in the South West Region per 100,000 of the population

	Ageband	Year of diagnosis				
		1991	1992	1993	1994	1995
<u>Age specific incidence rates</u>	0-4					
	5-9					
	10-14					1.0
	15-19					
	20-24					
	25-29		1.6	2.4		0.8
	30-34	0.8	0.8	1.6	0.8	0.8
	35-39	1.8	1.8	2.6	0.9	3.4
	40-44	12.4	9.7	1.7	5.0	3.4
	45-49	17.8	9.9	13.5	13.2	10.8
	50-54	23.2	21.9	17.2	18.5	19.6
	55-59	38.0	28.3	37.8	41.6	32.8
	60-64	65.6	64.2	70.0	60.6	36.7
	65-69	84.8	97.4	103.3	65.4	81.5
	70-74	121.6	139.4	108.1	121.0	118.4
	75-79	149.8	174.1	155.9	147.7	150.7
	80-84	223.2	233.5	213.0	219.3	235.6
	85+	321.5	274.4	252.2	236.5	263.8
<u>Age standardised incidence rates</u>	95% ucl	26.9	26.7	25.5	23.8	23.2
	ASR	25.0	24.7	23.6	22.0	21.4
	95% lcl	23.0	22.8	21.7	20.2	19.7
	s.e.	1.0	1.0	1.0	0.9	0.9

*Table 3: New registrations of males with colon cancer in the South West Region
per 100,000 of the population*

		Year of diagnosis					
Ageband		1991	1992	1993	1994	1995	1991-95
<u>Age specific incidence rates</u>	0-4						
	5-9						
	10-14						
	15-19	0.9					0.2
	20-24					0.8	0.2
	25-29	0.8	0.8				0.3
	30-34	4.2	0.8	2.4		1.5	1.7
	35-39	6.3	0.9	4.3	0.9	0.8	2.6
	40-44	6.3	6.6	6.8	3.4	3.4	5.3
	45-49	9.8	12.4	13.5	9.4	12.4	11.5
	50-54	22.3	23.1	31.4	28.2	29.0	26.9
	55-59	42.5	47.0	36.6	37.2	37.8	40.2
	60-64	76.7	83.8	58.3	76.0	78.8	74.7
	65-69	128.3	108.9	103.9	105.2	119.3	113.2
	70-74	180.2	154.2	173.4	185.2	199.2	178.7
	75-79	202.6	201.2	249.8	241.5	206.5	219.7
	80-84	279.8	290.7	303.6	284.3	275.4	286.7
	85+	307.8	311.7	390.2	349.2	316.0	335.1
<u>Age standardised incidence rates</u>	95% ucl	32.8	31.5	32.9	32.2	32.7	31.1
	ASR	30.4	29.2	30.5	29.9	30.4	30.1
	95% lcl	28.0	26.8	28.1	27.6	28.0	29.0
	s.e.	1.2	1.2	1.2	1.2	1.2	0.5

Table 4: New registrations of females with rectal cancer in the South West Region per 100,000 of the population

	Ageband	Year of diagnosis					1991-95
		1991	1992	1993	1994	1995	
<u>Age specific incidence rates</u>	0-4						
	5-9						
	10-14						
	15-19						
	20-24		0.8				0.2
	25-29			0.8			0.2
	30-34	0.8	0.8	0.8	1.6		0.8
	35-39	2.7	1.8	2.6	1.7	0.8	1.9
	40-44	5.4	4.9	3.3	2.5	2.5	3.8
	45-49	4.4	8.2	7.1	8.6	4.6	6.6
	50-54	8.4	16.7	13.1	9.7	10.3	11.6
	55-59	27.1	39.2	22.7	19.2	18.0	25.2
	60-64	25.6	35.2	32.4	25.5	24.8	28.7
	65-69	44.8	44.2	48.1	46.7	43.9	45.5
	70-74	64.1	60.7	57.1	74.8	50.0	61.4
	75-79	82.4	104.2	69.3	79.4	72.7	81.8
	80-84	114.1	95.0	102.5	91.5	75.4	95.5
	85+	109.8	156.5	112.9	81.7	93.4	110.0
<u>Age standardised incidence rates</u>	95% ucl	13.4	16.2	13.5	12.9	11.2	12.7
	ASR	12.0	14.6	12.1	11.5	10.0	12.1
	95% lcl	10.7	13.1	10.7	10.2	8.8	11.4
	s.e.	0.7	0.8	0.7	0.7	0.6	0.3

Table 5: New registrations of males with rectal cancer in the South West Region per 100,000 of the population

	Ageband	Year of diagnosis				
		1991	1992	1993	1994	1995
<u>Age specific incidence rates</u>	0-4					
	5-9					
	10-14					
	15-19					
	20-24			1.6		0.3
	25-29	0.8		0.7	0.7	0.6
	30-34	0.8	0.8			0.3
	35-39	0.9	1.8	1.7	2.6	1.9
	40-44	4.7	6.6	4.2	4.3	4.5
	45-49	8.9	14.0	10.3	14.9	11.8
	50-54	24.4	26.3	28.3	23.3	24.1
	55-59	35.8	50.4	54.4	43.7	46.2
	60-64	61.2	70.4	49.4	64.6	60.1
	65-69	75.6	66.7	67.3	91.0	73.8
	70-74	96.6	104.6	120.9	121.8	108.1
	75-79	130.1	163.2	146.7	148.6	138.4
	80-84	143.0	134.9	192.6	167.7	163.6
	85+	172.2	177.4	121.6	162.7	163.1
<u>Age standardised incidence rates</u>	95% ucl	21.7	24.3	23.4	24.7	21.2
	ASR	19.7	22.2	21.4	22.6	19.3
	95% lcl	17.8	20.1	19.4	20.6	17.4
	s.e.	1.0	1.1	1.0	1.1	0.5

Tables 2 to 5 show the age specific and age standardised incidence rates for all new registrations of colon and rectal cancers between 1991 and 1995 in the South West Region. The age specific and age standardised rates are expressed as registrations per 100,000 population.

Tables 2 and 3 describe the incidence rates of colon cancer in men and women in the South West region. It is evident that the incidence rates of male new registrations with colon cancer are greater than for women between the years 1991 and 1995. The age standardised incidence rate of

colon cancer for all years (1991 to 1995) in women is 23.3 (table 2), whereas the corresponding incidence rate in men is 30.1 (table 3). This means that men were more likely to be newly diagnosed with colon cancer than women between 1991 and 1995. However, it is also evident that up to the age of 49 the rate of new registrations of men and women was very similar. This suggests that the greatest difference in incidence occurred after this age (refer to the last column in tables 2 and 3). Further, table 2 shows that the rate of new registrations of colon cancer in women declined annually between 1991 and 1995. However, the rate of new registrations of colon cancer in men remained more stable during the same time period (table 3). Tables 2 and 3 show that the rate of new registrations of colon cancer increases with advancing age for both men and women. The rates remain relatively low in men and women up to the age of 39, and the incident rates increase dramatically after the age of 60.

*Table 6: *New registrations of females with colon cancer in Avon Health Authority per 100,000 of the population*

	Ageband	Year of diagnosis					1991-95
		1991	1992	1993	1994	1995	
<u>Age specific incidence rates</u>	0-4						
	5-9						
	10-14						
	15-19						
	20-24						
	25-29						
	30-34	2.8		5.3		2.5	2.1
	35-39	3.1	3.0			8.6	3.0
	40-44	16.6	14.4		2.9		6.9
	45-49	25.8	12.1	17.5	23.1	5.7	16.7
	50-54	19.0	18.9	18.3	7.2	10.5	14.6
	55-59	27.9	36.3	24.2	47.7	31.7	33.6
	60-64	62.9	31.6	75.2	52.3	28.5	50.2
	65-69	113.8	78.5	103.9	81.3	78.2	91.4
	70-74	115.3	182.3	96.5	117.7	106.1	123.4
	75-79	127.5	257.6	165.9	119.3	171.1	169.1
	80-84	171.0	188.3	218.5	286.2	247.4	222.8
	85+	361.6	267.1	252.1	252.1	233.3	271.5
<u>Age standardised incidence rates</u>	95% ucl	29.3	29.2	26.8	25.9	23.0	24.9
	ASR	25.4	25.5	23.2	22.4	19.8	23.2
	95% lcl	21.6	21.7	19.5	18.8	16.5	21.6
	s.e.	2.0	1.9	1.8	1.8	1.6	0.8

* South and West Cancer Intelligence Unit (1998)

*Table 7: New registrations of males with colon cancer in Avon Health Authority
per 100,000 of the population*

	Ageband	Year of diagnosis					1991-95
		1991	1992	1993	1994	1995	
<u>Age specific incidence rates</u>	0-4						
	5-9						
	10-14						
	15-19	3.1					0.7
	20-24						
	25-29						
	30-34	2.8	2.7			4.7	2.1
	35-39	3.1	3.0	8.8	2.9		3.5
	40-44	2.8	2.9	8.8		5.9	4.1
	45-49	9.6	12.0	11.6	11.4	11.4	11.2
	50-54	30.3	11.2	21.9	14.3	24.3	20.4
	55-59	40.4	44.9	28.4	56.0	47.8	43.5
	60-64	79.0	67.0	50.2	38.1	98.2	66.5
	65-69	119.4	95.2	136.9	77.8	91.5	104.3
	70-74	142.4	179.7	172.7	213.9	210.8	184.8
	75-79	261.2	188.6	203.4	251.6	197.9	220.3
	80-84	257.4	309.6	384.0	256.5	231.8	287.6
	85+	308.2	206.5	481.5	377.2	297.9	335.1
<u>Age standardised incidence rates</u>	95% ucl	34.6	30.7	35.9	32.6	34.9	31.2
	ASR	29.9	26.4	31.2	28.2	30.2	29.2
	95% lcl	25.3	22.1	26.5	23.7	25.6	27.2
	s.e.	2.4	2.2	2.4	2.3	2.4	1.0

Table 8: New registrations of females with rectal cancer in Avon Health Authority per 100,000 of the population

	Ageband	Year of diagnosis					1991-95
		1991	1992	1993	1994	1995	
<u>Age specific incidence rates</u>	0-4						
	5-9						
	10-14						
	15-19						
	20-24						
	25-29						
	30-34		2.7		2.6		1.1
	35-39		3.0	3.0			1.2
	40-44		0.0	5.9		3.0	1.7
	45-49		3.0	2.9	2.9	2.9	2.4
	50-54	3.8	7.6	25.7	10.8	13.9	12.4
	55-59	19.9	24.2	24.2	15.9	23.8	21.6
	60-64	35.4	31.6	19.8	12.1	4.1	20.7
	65-69	22.8	43.2	52.0	56.9	41.2	42.9
	70-74	42.7	58.0	68.4	66.7	40.8	55.6
	75-79	68.6	94.1	41.5	81.4	82.9	73.8
	80-84	118.4	116.9	115.7	57.2	50.8	91.4
	85+	120.5	115.5	126.0	68.1	80.0	101.3
<u>Age standardised incidence rates</u>	95% ucl	11.4	14.4	15.2	12.2	11.2	11.5
	ASR	9.2	11.8	12.4	9.8	8.8	10.4
	95% lcl	6.9	9.2	9.7	7.5	6.5	9.3
	s.e.	1.1	1.3	1.4	1.2	1.2	0.6

Table 9: New registrations of males with rectal cancer in Avon Health Authority per 100,000 of the population

	Ageband	Year of diagnosis					1991-95
		1991	1992	1993	1994	1995	
<u>Age specific incidence rates</u>	0-4						
	5-9						
	10-14						
	15-19						
	20-24			2.5			0.5
	25-29					2.3	0.5
	30-34						
	35-39		3.0	5.9	2.9	2.8	2.9
	40-44	5.6		8.8	5.9	2.9	4.6
	45-49	16.0	17.9	8.7	11.4	14.2	13.6
	50-54	26.5	22.5	32.9	14.3	13.9	21.8
	55-59	32.3	61.2	40.6	40.0	51.8	45.1
	60-64	54.1	50.2	37.7	59.3	55.5	51.3
	65-69	75.2	54.4	41.1	68.7	91.5	66.2
	70-74	85.4	98.0	120.4	137.5	131.7	115.3
	75-79	156.7	150.9	172.1	89.3	137.0	141.8
	80-84	167.3	136.2	276.0	163.2	162.3	181.2
	85+	198.2	137.6	65.7	230.5	238.3	176.1
<u>Age standardised incidence rates</u>	95% ucl	24.3	24.0	24.4	24.2	26.8	22.6
	ASR	20.4	20.1	20.5	20.4	22.8	20.9
	95% lcl	16.5	16.2	16.7	16.5	18.7	19.1
	s.e.	2.0	2.0	2.0	2.0	2.1	0.9

Tables 4 and 5 show the age specific and age standardised incidence rates of men and women with rectal cancer in the South and West Region. The rate of new registrations of men with rectal cancer is higher than that of women between 1991 and 1995. As with colon cancer, the incidence rate of rectal cancer increases with advancing age in men and women between the years 1991 and 1995. The age standardised incidence rates of women show that a slight decrease has taken place between 1991 and 1995. However, among men the rate of new registrations had increased after

1991 and remained stable until 1994. Then the incidence rate decreased back to approximately the original level of 1991. The incidence rates for the years 1991 to 1995 remained similar in both men and women up to the age of 44 and increased sharply in subsequent age-bands.

Tables 6 to 9 depict the age-specific and age-standardised incidence rates in Avon for men and women with colon and rectal cancer between 1991 and 1995. The incidence rate of women diagnosed with colon cancer between 1991 and 1995 fell from 25.4 per 100,000 in 1991 to 19.8 per 100,000 in 1995 (Table 6). However, the incidence rate of men with colon cancer remained more stable at 29.9 per 100,000 in 1991, changing to 30.2 per 100,000 in 1995. It is also evident from tables 6 and 7 that the overall incidence rate of colon cancer for women for all years 1991 to 1995 was 23.2 per 100,000, and 29.2 per 100,000 for men. This compares favourably with the incidence of colon cancer in men (30.3) and women (24.3) in the population of England and Wales. Men were, therefore, more likely to be diagnosed with colon cancer than women between 1991 and 1995. Further, the rate of colon cancer among men and women for the years 1991 and 1995 increases progressively with age. For instance, in 1995 the rate of colon cancer for men and women between the ages of 60 and 64 was 98.2 and 28.5 per 100,000 of the population respectively, which increased to 197.9 for men and 171.1 for women between the ages of 75 and 79. This increase in the incidence of colon cancer among men and women is similar to that of the trend for the population of England and Wales in 1992 (table 1).

Table 10: Total number of new presentations to Bristol Oncology Centre between 1/1/96 and 31/12/96

Male	No of presentations	Female	No of presentations
25	1	25-29	
30-34		30-34	1
35-39		35-39	
40-44	3	40-44	
45-49	5	45-49	7
50-54	8	50-54	10
55-59	21	55-59	13
60-64	19	60-64	25
65-69	36	65-69	27
70-74	47	70-74	37
75-79	49	75-79	39
80-84	29	80-84	18
85-89	6	85-89	9
90-94		90-94	4
95-99		95-99	
100-104		100-104	1
Colon	103	Colon	98
Rectum	121	Rectum	93
Duke's Stage A	3	Duke's Stage A	6
B	48	B	38
C	89	C	71
D	32	D	24
Unclassified	52	Unclassified	52

Although the incidence of colon cancer in men is slightly higher than in women, the rate of rectal cancer in men was approximately twice that in women between 1991 and 1995 for most age groups (tables 8 and 9). For instance the age standardised incidence rate of rectal cancer in women for all years 1991 to 1995 was 10.4 per 100,000 of the population, and 20.9 per 100,000 of the population in men. These rates are slightly lower than those for England and Wales in 1992, which are 12.3 in women and 22.8 in men per 100,000 of the population. It is also evident that the incidence rate of colon cancer in men and women in Avon Health Authority is higher than the incidence of rectal cancer, which is similar to the national and regional rates.

Table 10 illustrates the total number of new presentations to the Bristol Oncology Centre between 1/1/96 and 31/12/96. The number of new presentations to the oncology centre over the age of 65 is much greater than the number of new presentations under the age of 65. This trend is consistent with the incidence of colorectal cancer in the UK, the South West region, and in Avon Health Authority. The annual number of female patients with colon cancer (98) presenting to the oncology centre is similar to the number of male patients (103). This is consistent with the incidence rate for the population of England and Wales, the South West, and Avon, where men have a slightly higher incidence of colon cancer. Furthermore, the number of annual male and female rectal cancer presentations to the Oncology Centre is consistent with the national, regional, and local incidence rates.

Table 10 shows the distribution of men and women who have been referred to the oncology centre during 1996 by stage at diagnosis. The most frequent tumour stage at diagnosis for both men and women is Duke's C, followed by Duke's B, D and finally A. Thus, the majority of annual presentations to the Oncology Centre were patients with Duke's B and C colon and rectal cancer. However, a total of 104 cases have been unclassified and caution should be exercised when interpreting these figures.

Table 11: Total number of new presentations of colon and rectal cancer to Bristol Oncology Centre during recruitment period 1/1/96 to 23/9/96

Male	No of presentations	Female	No of presentations
20-24	1	20-24	
25-29		25-29	
30-34		30-34	1
35-39		35-39	
40-44	2	40-44	
45-49	4	45-49	6
50-54	5	50-54	7
55-59	14	55-59	12
60-64	15	60-64	20
65-69	25	65-69	24
70-74	38	70-74	25
75-79	40	75-79	27
80-84	23	80-84	13
85-89	3	85-89	5
90-94		90-94	3
95-99		95-99	
100-104		100-104	
Colon	74	Colon	76
Rectum	96	Rectum	67
Duke's Stage A	3	Duke's Stage A	4
B	40	B	35
C	63	C	48
D	24	D	21
Unclassified	40	Unclassified	35

Table 11 depicts the number of new presentations of colon and rectal cancer to Bristol Oncology Centre during the recruitment period. It is evident that the proportions of new patients attending the oncology centre over the ten-month recruitment period are consistent with the annual referral numbers to the Oncology Centre. For instance, there are at least twice as many new patients over the age of 65 presenting to the oncology centre than patients under the age of 65. Also, a greater number of males than females presented with rectal cancer, and a marginally higher number of females than males presented with colon cancer. Again, the distribution of colon and rectal cancer

is consistent with the incidence of colon and rectal cancer in the wider population of England and Wales, the South West region, and Avon Health Authority. Table 11 indicates that the most common tumour stage at time of presentation was Duke's C and B, followed by D and A. Thus, patients with either very early or far advanced disease were least likely to be attending the Oncology Centre.

Table 12 illustrates the number of new cases with colon and rectal cancer attending the weekly clinic and the proportion of consultations observed between 1/1/96 and 23/9/96. A total of 189 new presentations with colon and rectal cancer attended the outpatient clinic during the ten month recruitment period. The total number of patients who were included in the observation study was 55, which is approximately one third of the total number of attendees. The main reason why approximately only one third of patients were observed was that many consultations with new patients were not suitable for the purposes of the study because they had already discussed the treatment options with the oncologist prior to attendance at the oncology centre. In addition, some registrars working in the clinic did not always provide an invitation to attend a consultation, which inevitably meant that some patients would fall through the net. Also, my absence from some of the clinics due to interview commitments, contributed to a lower accrual of observations.

Table 12: Numbers of new cases attending weekly clinic and numbers actually observed between 1/1/96 and 23/9/96

Attending Clinic between 1/1/96 and 23/9/96	Number of New Cases	Total Number Observed
30-34	1	
35-39		
40-44	1	
45-49	7	1
50-54	5	1
55-59	17	4
60-64	21	8
65-69	30	12
70-74	36	19
75-79	38	7
80-84	27	2
85-89	6	1
Colon	85	28
Rectum	104	27
Duke's Stage A	3	0
B	48	10
C	75	37
D	29	8
Unclassified	34	0
Male	81	37
Female	108	18

The data indicate that approximately two thirds of new patients attending the oncology centre and two thirds observed in consultations between 1/1/96 and 31/9/96 were over 65 years old. Also, a greater number of cases with rectal cancer than colon cancer presented at the clinic, which is inconsistent with local, regional, and national incidence rates for the two tumour sites. The proportion of cases with colon and rectal cancer presenting at the weekly clinic during the observation period, is similar to that attending the oncology centre during the whole of 1996 as illustrated in tables 10 and 12.

Table 12 further shows that the most common group of patients attending the clinic during the observation period had a Duke's stage C cancer, followed by stage B, D, and A. These proportions are consistent with the total number of cases observed for the study. The national and regional incidence rates for males and females with colon and rectal cancer are similar to the proportion of patients presenting during the recruitment period (refer to tables 1-6). However, the gender distribution of colon and rectal cancer cases begins to change for new referrals to the Bristol Oncology Centre during 1996, whereby 224 are male and 191 are female (table 10). This trend continues for all new presentations to the oncology centre for the observation period 1/1/96 to 23/9/96, during which 170 males and 143 females were referred (table 11). However, this trend changes yet again for all new referrals attending the weekly clinic during the observation period, where the number of female presentations is higher than for males. The bar chart below illustrates this trend.

Figure 3: Regional and local incidence of colorectal cancer, and total number of cases attending Bristol Oncology Centre

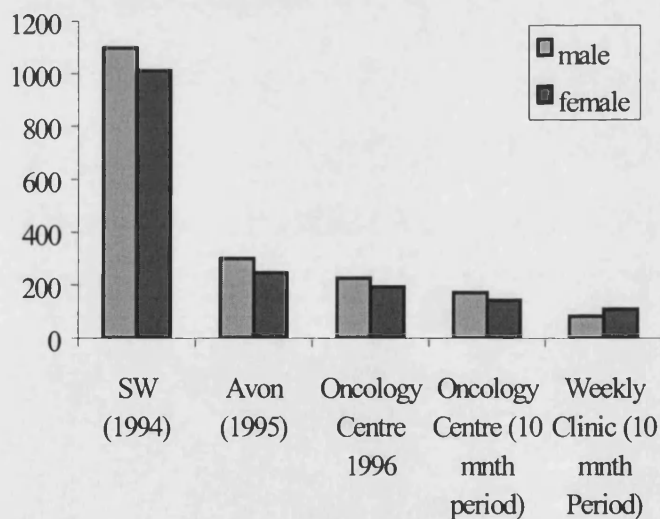


Table 13 illustrates the total number of new referrals to the oncology centre who were approached to participate in an interview and the final number who agreed to participate. A total of 55 patients were approached for an interview, of whom 37 participated (24 men and 13 women) representing a response rate of 67%. A larger number of men than women were approached (38

men and 17 women), of whom 14 men and 4 women refused to participate. It is interesting that 17 out of the 18 refusals were aged over 65. It could be that older patients are less likely to participate in general. Conversely, the data show that approximately 25% (14 out of 41 patients) of patients who were approached for interview were under 65 years of age, and this proportion increased to approximately 33% of the total number of patients interviewed. This indicates that younger patients were more willing to participate in an interview or that older patients were less likely to participate.

Table 13: Characteristics of patients approached for interview

Patients Approached	Total Number Approached	Refused	Agreed
Male	38	14	24
Female	17	4	13
(37-64) Under 65	14	1	13
(65-80) Over 65	41	17	24
35-39			1
40-44			
45-49	1		1
50-54	1		1
55-59	4	1	4
60-64	8		6
65-69	12	8	7
70-74	19	6	11
75-79	7	2	5
80-84	2		1
84-89	1	1	
Colon	32	10	22
* Rectum	23	8	15
Duke's Stage B	8	6	2
C	37	9	28
D	10	3	7
Total	55	18	37

* The classification of rectal cancer includes all cases of rectum and recto-sigmoid junction

In 1992 approximately one quarter of cases with colorectal cancer were under the age of 65 in England and Wales. The proportion of patients above and below the age of 65 for the South West region and Avon Health Authority are similar. In comparison to the current study, 13 patients under the age of 65 and 24 over the age of 65 agreed to an interview. Thus, approximately one third of all interviewees were under the age of 65. This represents a greater proportion under 65 than could be expected nationally, regionally, and locally.

Table 13 shows that 32 patients with colon cancer and 23 patients with rectal cancer were initially approached for an interview, and 22 with colon cancer and 15 with rectal cancer finally agreed to participate. The ratio of patients with colon and rectal cancer who agreed to be interviewed is consistent with the national, regional and local proportions of cases with colon and rectal cancer.

The number of colorectal cancer cases by tumour stage, presenting to the Oncology Centre also follows a consistent pattern. For instance, in 1996 and during the recruitment period 1/1/96 to 23/9/96, the rate of presentations with Duke's C colon and rectal cancer was highest followed by Duke's stage B and then D (Table 11, 12 and 13). The majority of patients who were approached for an interview, as well as those who finally agreed to participate in an interview, had Duke's stage C disease followed by stage D (most advanced) and then stage B. Those with a Duke's stage B cancer were most likely to decline participation in an interview, where 8 were approached and only 2 agreed to an interview.

The total number of patients approached for the study was influenced by several factors which have already been discussed elsewhere (see chapter 3). The patients approached for interview at the clinic were selected as a 'convenience' sample whereby all new presentations at the oncology centre were asked to participate.

The referral patterns of surgeons can determine the kinds of patients attending the oncology centre. For instance, patients with Duke's B cancer who were less likely to be referred in the past are more likely to be referred today due to patient demand. Also, patients are more likely to undergo treatment as part of a clinical trial, which in turn increases demand for therapy. Thus, the types of patients who are referred to the oncology centre will significantly affect the nature of the study sample. During the recruitment stage of the study the oncologist in charge sometimes advised that certain patients should not be approached for an interview due to physical or psychological reasons.

Living status of interview participants

Table 14: Living status of interview respondents

Living Status	Living Alone	^a Living with Significant Other
Male	5	19
Female	4	9
35-39		1
40-44		
45-49		1
50-54		1
55-59	1	3
60-64	1	5
65-69	2	5
70-74	3	8
75-79	1	4
80-84	1	
^b Had Treatment	5	18
Had No Treatment	4	10
Total	9	28

The majority of interviewees lived with one other close relative, usually a spouse. However, most of those who lived alone tended to be aged over 65 years suggesting that their living status could have been affected by the death of a spouse. Women were much more likely than men to be living alone due to the death of a spouse. For instance, out of a total of 13 females interviewees 4 lived alone, whereas out of 28 male interview participants only 5 lived alone. Also, there appears to be a positive relationship between having no treatment and living alone. For instance, of the 23 interviewees who had treatment, only five lived alone (approximately 25%). Although, out of the 14 informants who had no treatment, 4 lived alone (approximately 33%). This may indicate that living alone can act as a barrier from undergoing treatment.

^a In the vast majority of cases the 'significant other' was a spouse.

^b Either palliative or 'adjuvant' treatment, including chemotherapy, radiotherapy, or a combination.

Attrition rate of interview participants

Table: 15 Attrition rate of interviewees due to poor health and death

Patient Characteristics	Withdrawal due to Poor Health	Withdrawal due to Death
Male	5	3
Female	0	1
(Age) 60-64	1	1
65-69	2	2
70-74	1	1
75-79	1	
80-84		
Colon	5	3
*Rectum	0	1
Duke's Stage B	0	0
C	3	2
D	2	2
Total	5	4

Out of 37 informants who participated in the first interview, 9 were unable to attend the follow-up interview due to deteriorating health and death.

Table 15 shows that 8 out of 9 non-responders to the second interview were male, all were over 65 with colon cancer, and most had advanced disease (Duke's C or D). Although the majority of patients attending the Oncology Centre had Duke's C stage disease, it is evident from the data that a disproportionate number of interviewees who withdrew from the second interview had advanced stage disease (Duke's D). Out of the seven informants with Duke's D cancer who originally agreed to participate in an interview, 4 declined by the time of the follow-up. The primary reason for withdrawal from the follow-up interview was poor health and death due to advanced disease. The non-responders to the follow-up interview represented a population of patients with advanced disease who may have differed in their longer-term views towards decision-making. Thus, the responses that were obtained from the informants at the follow-up interviews may be representative of individuals who have relatively better health.

* The classification of rectal cancer includes all cases of rectum and recto-sigmoid junction

Table 16: Overall attrition rate

Patients Characteristics	Total Number Approached	Informants at 1st Interview	Informants at 2nd Interview
Male	38	24	16
Female	17	13	12
35-39		1	1
40-44			
45-49	1	1	1
50-54	1	1	1
55-59	4	4	4
60-64	8	6	4
65-69	12	7	3
70-74	19	11	9
75-79	7	5	4
80-84	2	1	1
85-89	1		
Total	55	37	28

Table 16 illustrates the attrition rate as a result of the initial refusal to participate in an interview, and subsequent withdrawal from the follow-up interview due to poor health and death. From all 55 patients who were initially approached for an interview, 28 were interviewed on two occasions. It is evident that although most patients who were initially approached for an interview were male, the final distribution of males and females attending the follow-up interview was more equal. This suggests that in this study the withdrawal rate was the lowest among women. This could be because female responders had less advanced disease or because they were more willing to participate in an interview. Furthermore, patients over the age of 65 were most likely to refuse the initial invitation to participate and also withdraw by the time of the follow-up interview due to poor health and death.

The interviewees

New patients attending a consultation at the oncology centre typically came with a supporting close relative (usually a spouse) or a friend. Patients were usually unaware of the form or content of the consultation prior to attendance, and not surprisingly there was usually an air of apprehension and nervousness during the meeting with the oncologist. The attendance of relatives and friends sometimes affected the dynamics of the interactions as consultations often involved a three or a four-way conversation. Thus, initially the level of patient involvement in the consultation was minimal, but patients frequently became more active in the interaction as the consultation progressed. The patients attending the clinic tended to be over 60 years of age and there was an equal proportion of men and women.

However, the interviews with patients provided an insight into their personal lives and experiences, and helped to place the informants in their social and domestic context. This way it was easier to identify the underlying reasons for the decisions that informants had made. The interviews also provided an opportunity for learning more about the informants in terms of the types of people that they were.

The majority of the informants were married (28 out of 37) or living with a partner, and most had adult children. The interviews revealed that many informants were articulate and had well formed views about cancer treatment and the cancer diagnosis. In a few interviews the informants sometimes had difficulty expressing their views, but on the whole they were able to engage in a productive discussion of their role in treatment decision-making. There were no obvious differences in views expressed between informants from different socio-economic groups. Also, there were few differences in the views expressed between men and women.

The interviews frequently turned to a discussion of the informants' personal experiences of living and coping with cancer, and on a few occasions it became difficult to change the focus of the interview as informants were more concerned with a discussion of 'their life with cancer'. What was also very striking about the informants was their tremendous optimism about their affliction and their determination to fight it despite the odds. Even terminally ill informants often appeared resolved to 'fight' their disease, rather than accept their fate. To some extent this was their way of coping with a life threatening condition, but it might also have been the result of undergoing prolonged treatment which gave them the confidence that something positive and rigorous was being done about their cancer. However, underlying their optimism many informants also showed signs of worry and anxiety concerning their illness during the interview. Indeed, many of the interviews were emotionally charged and in several instances informants 'broke down'. However, none of the informants blamed the actual interview process for evoking anxiety or worry. Indeed, most claimed that they benefited from discussing various issues relating

to their illness with a 'neutral' party, when asked if they found the interview helpful. In most cases the interview seemed an anxiety free experience that some informants used to clarify certain issues for themselves, or re-interpret certain difficulties in their own minds. It was an opportunity also for some of them to think about issues that they perhaps had not thought about previously. For instance, when they were probed to show how they understood the risks and benefits of the treatment options that they were given.

Female interviewees were more likely than males to be living alone although most lived with a spouse and a few had children living at home. Having children or grandchildren frequently figured highly as a topic of discussion, and it was often a pivotal reason for the treatment decisions that these informants made. Children or grandchildren often gave them an extra reason for maintaining their fight against cancer. Present in most interviews were the informants' relative or relatives who also participated in the discussion. Members present at the interviews were typically the informant's spouse, children or siblings. These people were closely involved in their relative's illness and usually played some part in helping the relative reach a treatment decision.

Three of the interview informants were significantly younger than the rest: one woman of 37 (social worker) another 49 (masseuse) and one man who was 53 years of age (electrical engineer). However, although they were younger and with higher educational qualifications, they did not seem any more articulate or better informed about their condition than many older informants who did not have a high level of education. This might be partly related to the lower public profile of colorectal cancer as compared with breast cancer. Occupational standing varied widely and included, among many other occupations, aerospace engineers, managers, school teachers, factory workers, and caterers. Most informants, regardless of occupational status, seemed to have elaborate views about their illness and the treatment decision-making process. Thus, few informants played an entirely 'passive' part in debating and evaluating the risks and benefits of treatment. During the interviews it became evident that most informants debated the pros and cons of treatment with relatives or friends, at least to some extent.

Certainly, there were some informants who did not partake in a discussion of the pros and cons of treatment with their friends or relatives, as they did not believe that they had any role to play in the decision-making task. This was thought to be the clinician's responsibility. This lack of participation in any assessment of the pros and cons of treatment became evident during the interviews when they demonstrated little willingness to even open the issue for discussion. Engaging in a limited dialogue regarding the appropriateness of treatment was their way of coping with a difficult decision that they preferred the clinician to make. However, most informants did participate in a prolonged discussion in the interview of how and why they reached a treatment decision.

Some of the interviews (7 out of 37) were conducted with terminally ill patients, which differed to the other interviews in the sense that the informants were aware of the seriousness of their

condition and that death was likely. The interviews tended to focus on matters of life and death and informants frequently became distressed as a result. An in-depth discussion of the treatment options was not entirely relevant to their concerns during the last stages of their illness. Although most informants who were terminally ill were aware of their imminent death, they also appeared to be hopeful that treatment might possibly prolong their lives. In contrast, most of the informants who were not terminally ill (30 out of 37) tended to invest much more hope in the prospect of full recovery. Thus, the interviews with this group of informants tended to have a much stronger emphasis on the pros and cons of treatment, and the decision-making task.

Interviews with members of staff

Individual characteristics

In chapters 6 and 7 pseudonyms were used instead of the real names of members of staff of the oncology centre and Avon Health Authority, in order to protect their identity.

There were five oncologists who led the consultations during the study period: a male lead consultant in clinical oncology * (Dr Tom Fenton who was approximately 35 years old), and a female senior registrar in clinical oncology (Dr Anne Smith who was approximately 40 years old). However, 10 consultations were also conducted by a male Professor in clinical oncology during the study period (Dr Mark Hutton who was approximately 45 years old), and two female registrars in clinical oncology (Dr Jane Richards and Dr Victoria Bench who were both approximately 35 years old). These five oncologists formed the basis of all the consultations that were conducted during the course of the study.

Five interviews were also conducted with nursing staff working in the colorectal cancer clinic. The nurses included two senior nurses: a sister who had overall responsibility for managing the clinic and a staff nurse who conducted 'support' duties for the oncologists. The other three nursing staff were junior nurses who carried out more 'routine' tasks involving the collection of blood samples, discussing treatment options with patients following their consultation, and

* Only the approximate ages of members of staff are provided, as this information was not collected during the fieldwork.

general nursing duties. These nurses also worked on the ward as well as the colorectal cancer clinic. Interviews were conducted with the nurses at different times during the course of the study in order to obtain information regarding their views of caring for cancer patients, work pressures, and their general experiences of nursing in an oncology department. The interviews were conducted to provide background knowledge about the experiences of nurses, which helped to inform the analysis task and the search for new themes during the observations and interviews with patients.

The policy background chapter was based on interviews conducted with Dr Mark Hutton (Professor in clinical oncology), Dr James Harris (clinical director of the oncology centre at the time of the study – approximately 50 years old), and Dr Maureen Davis who works at Avon Health Authority and is responsible for commissioning cancer services. She is approximately 40 years old.

The interviews (oncologists)

Personal interviews were conducted with four oncologists working at the oncology centre: Dr Tom Fenton (consultant clinical oncologist), Dr Mark Hutton (Professor of clinical oncology), Dr Anne Smith (senior registrar in clinical oncology), Dr James Harris (clinical director of the oncology centre). Also one interview was conducted with Dr Maureen Davis who is responsible for commissioning cancer services at Avon Health Authority.

The interviews with the oncologists were exploratory and were conducted at different stages during the fieldwork, so that new or emergent issues could be tested during interviews with oncologists at various points in time. The interviews were conducted for two purposes. First of all, to examine the views of clinicians regarding treatment decision-making, in order to provide a clinical as well as a patient perspective on the decision-making process. Secondly, to cast some light on how the oncology centre was organised, the financial pressures that it was experiencing, and how these factors might impinge on patient care. The latter was particularly useful in providing information for chapter 6 (the social and policy context). An interview was also conducted with a member of Avon Health Authority responsible for commissioning cancer services, to examine the wider purchasing, commissioning and contracting strategies in the region. The interviews typically lasted between 45 and 60 minutes and issues relating to decision-making and information disclosure were explored with the oncologists. Practice styles and the ways that oncologists disclose medical concepts and information to patients were also discussed. The interviews provided a means of testing various ideas with oncologists that emerged from the

interviews with patients and the observations. Conversely, several themes that stemmed from the interviews with the oncologists were subsequently tested in interviews with patients and observations of consultations. This helped to strengthen the validity of the data that was obtained from the patient interviews and particularly from the consultation episodes. Thus, these interviews provided a further means of cross checking emergent themes. The interviews were tailored according to the individual responses and circumstances of the clinicians. However, several general issues were raised with all oncologists. These were issues relating to the decision-making practices of oncologists and their role in communicating information to patients.

Although there is a much greater emphasis on site-specialisation in the oncology centre, most oncologists still specialise in different cancer sites. However, all the oncologists that were interviewed had a special interest in colorectal cancer. Consequently, oncologists were usually able to provide comparative information on the decision-making practices and disease profiles of patients with different disease types. Thus, useful information on the patient profile was obtained which helped to locate colorectal cancer patients within the wider population of cancer patients attending the oncology centre.

The interviews (nurses)

Five interviews were conducted with nurses in order to investigate their experiences of caring for patients with colorectal cancer, their views about communicating information to patients, and work pressures. All the nurses that were interviewed were female, and although their specific ages were not gathered during the interviews, three of the junior nurses were approximately 20, 21, and 23 years of age. The sister and the staff nurse were approximately 30 and 40 years of age respectively. As with the interviews with oncologists, these interviews were conducted at various stages of the fieldwork in order to explore issues and themes raised in the interviews and the observations. The interviews provided valuable background information about the way the oncology centre operated on a daily basis and the responsibilities that were carried out by the nurses working with the cancer patients. Each interview began with a general question about the nurses' role in patient care and subsequently narrowed in on specific issues deemed important by the nurses. The interviews were based on a less structured format than the interviews with the colorectal cancer patients and questions were not 'standardised' across all informants as interviews were specific to each oncologist's and nurse's individual responsibilities and routines. Issues and routines that were identified during the time spent at the oncology centre were raised

and explored during the interviews with the nurses and the oncologists, and any emergent themes were examined in subsequent interviews.

Conclusion

This chapter illustrated the characteristics of the study population and indicated from where the sample has been drawn. Firstly, the incidence rates of colon and rectal cancer in England and Wales, the South West region, and in Avon Health Authority were described. Secondly, the rate of new presentations with colon and rectal cancer to the Bristol Oncology Centre during the course of 1996 were described, as well as during the recruitment period, to illustrate the population of patients from which the final study sample was drawn. The chapter indicated that the characteristics of patients observed during the course of the ten-month period were generally representative of the annual population of colorectal cancer patients attending the oncology centre. The sample of patients who agreed to participate in the first interview also shared similar characteristics to the larger group of annual colorectal cancer referrals with regards to age, sex, tumour stage and site. Further, the interviewees consisted of a larger proportion of men than women, and the majority were over 65 years old. Finally, the chapter showed that the main reason for non-response to the second interview was the result of poor health and death. Also, the overall withdrawal rate as observed from the time when patients were approached for interview to the number who finally agreed to a second interview, was almost 50%. Therefore, a high attrition rate should be anticipated in future research on patients with colorectal cancer.

CHAPTER 6

SOCIAL POLICY CONTEXT OF CANCER CARE DELIVERY

Introduction

The purpose of this chapter is to discuss some of the changes facing the delivery of cancer care. Cancer services have undergone dramatic changes in the last decade, culminating in a report commissioned by the Expert Advisory Group on Cancer in 1995 (Calman-Hine Report, 1995) which drew out a list of recommendations of how cancer care should be organised. This chapter will review how far policies of Avon Health Authority, and Bristol Oncology Centre in particular, reflect the recommendations set out in the Calman-Hine report.

Health care in the UK is experiencing financial pressures due to escalating costs of services and treatments, and as a result the guiding principle of health care which used to be to provide free treatment at the point of use, has shifted to a greater emphasis on priority setting and accountability in the use of resources. Health authorities are placing more pressure on providers to deliver care in the most effective and efficient way. In this chapter some of these issues, and how they relate to cancer care in particular, are discussed. The fiscal pressures experienced by providers, and their responses to such pressures, will be explored with special reference to the Bristol Oncology Centre. The recommendations of the Expert Advisory Group on Cancer have indicated the need for cancer services to place greater emphasis on primary care and multidisciplinary team work in the care of patients (Calman-Hine, 1995). The possible implications of this policy will be evaluated, and in particular, how far resources are cost shifted from the secondary to the primary care sector. The chapter will further examine the current contracting practices of health authorities regarding cancer care, in particular, the tendency to place much more importance on the 'cost-effectiveness' of treatments, equity in service delivery, and better audit. Also, the issue of priority setting with regards to 'marginal' treatments has divided health authorities. The strategies which purchasers use when faced with difficult resource allocation decisions will be discussed, and how the use of clinical protocols has enabled them to divert conflict with clinicians and the public at large.

Finally, the Advisory Group recommendations advocate the centralisation of cancer services in order to provide a more effective as well as cost-effective service to cancer patients. Some of the

advantages and disadvantages of specialist care, such as site specialisation and multidisciplinary 'team work' which are recent developments in cancer care, will be discussed.

This chapter uses information gathered from interviews conducted with 2 oncologists and one manager at Avon Health Authority who is involved in commissioning cancer services. The oncologists included the director of the oncology centre, Dr James Harris, and Dr Mark Hutton (Professor of clinical oncology). Dr Davis is a manager at Avon Health Authority. Pseudonyms have been used to hide the identity of the interviewees.

Pressures of patient throughput

Bristol Oncology Centre is part of the United Bristol Healthcare Trust (UBHT) and is mainly concerned with the treatment and care of cancer patients. Patients are commonly referred to the Oncology Centre via a specialist from a regional hospital, and many of those who are referred have previously undergone surgery for their disease. Most patients are referred for a 'second opinion' regarding their suitability for further treatment which could involve either radiotherapy, chemotherapy, or a combination of both treatments. The nature of oncological therapy is such that it commonly aims to improve the survival chances of patients and their quality of life, but does not necessarily set out to achieve a 'cure'. Therefore, many attendees at the Oncology Centre have a worse health state and a less favourable prognosis than cancer patients who have been 'cured' by surgery and who, therefore, have not been referred to the Oncology Centre.

However, the patient profile at the Oncology Centre also depends on the type of cancer that patients have, and on the proven effectiveness of oncological treatments that are available. In the case of colorectal cancer, patients with less advanced disease are less frequently referred for chemotherapy because treatment has not been shown to improve survival. However, for patients with advanced disease further treatment has been shown to improve survival and they would therefore be referred.

The patient profile will vary according to cancer site, and traditionally patients who are referred to the Oncology Centre tend to have a worse prognosis. However, this pattern is starting to change as a result of 'supplier led demand'. The increasing provision of chemotherapy treatment in recent years, largely due to externally funded clinical trials, has resulted in attracting larger numbers of referrals. As a result, many of the cancer patients attending for treatment are not necessarily those with more serious disease. This is because cancer trials are now being conducted to evaluate treatment benefit both on patients with advanced, as well as early, cancer.

According to the clinical director at Bristol Oncology Centre, there has been an increase of 7% to 8% in the number of referrals per year. This is partly explained by the growing numbers of elderly people who are more likely to have cancer anyway, and as a result of greater public awareness about cancer. Another reason for the sharp increase in the numbers of patients attending the Oncology Centre is the expansion in consultant posts.

Dr Harris: Because we have more consultants than we did five years ago there are more patients having the opportunity to see an oncologist, whereas five years ago they may not have had that opportunity (Interview 39, p6).

The increasing patient throughput is leading to an even greater demand on the resources of the Oncology Centre. Some clinical departments can impose limits on the numbers of patients that they see for instance, through determining the length of waiting times more easily. However, new referrals to the Oncology Centre are often regarded as urgent which means that consultants may not be able to limit the numbers of referrals they get quite as easily as other departments can. Certainly, much of a consultant's time is taken up monitoring patients, sometimes as regularly as once every month throughout the duration of the treatment cycle that can last for six months or more. According to figures published by Avon Health Authority, there has not been a dramatic increase in the numbers of patients attending the Bristol Oncology Centre in the last eight years. Nevertheless, the numbers of Finished Consultant Episodes (FCEs) has increased successively in that time period. According to a Briefing Paper produced by Avon Health Authority, the number of Finished Consultant Episodes has increased from just over 1500 in 1990 to nearly 4000 in 1996, which is almost a three-fold increase in six years (Briefing Paper for the Executive Team, Avon Health Authority, 1996).

The increase in consultant workload can be attributed to the increasing use of chemotherapy and radiotherapy treatment, which involves patients attending for treatment on several occasions. As a result, each day case attendance is recorded for each patient who attends, regardless of whether that patient has already attended on a number of different occasions. This means that each patient is recorded several times as a Finished Consultant Episode. Of course, this is misleading and may suggest an increase in the overall numbers of new attendees at the Oncology Centre. Before the widespread use of chemotherapy for the treatment of cancer, the pressures on consultant workload were much smaller. However, new developments in the treatment of cancer have led to greater treatment costs, which have not been matched with proportionate revenue according to the clinical director of the Oncology Centre.

Dr Harris: There's a tendency for our work to be more complex and our

cost to exceed the average. This is why we've come under some pressure, as the number's are increasing, the complexity's increasing, to some extent the income is increasing. In spite of that our workload has continued to rise. We had to make some constraints on what we do (Interview 39, p3).

Another consultant in oncology claimed that:

Dr Hutton: In here, two hundred thousand comes in and has to be divided internally. The big difference is that drug treatment, you can scale it. Instead of giving it to ten people you give it to one person. You either have radiotherapy treatment or you don't, so you're very limited in your flexibility. There has been an increase in the numbers of bowel patients, and certainly in bowel cancer chemotherapy has not been considered a standard worthwhile treatment even five years ago, whereas now the vast majority of places give treatment (Interview 44, p7).

The number of day case episodes treated in the Oncology Centre has risen from 500 in 1990 to almost 3000 in 1996, almost a six-fold increase. At the same time the number of inpatient elective Finished Consultant Episodes has marginally decreased from about 700 in 1990 to approximately 500 in 1996. This indicates that the increase in consultant workload has been due to the dramatic expansion in day case treatment (most noticeably in colorectal cancer) brought about by new developments in cancer drugs (Briefing Paper for the Executive Team, Avon Health Authority, 1996).

Effects of cost pressures

Some oncologists have responded to the pressure of increasing patient numbers in various ways. For instance, one oncologist in charge of colorectal cancer patients attempted to introduce nurse-led clinics, in which patients attending for a follow-up appointment could consult a nurse rather than an oncologist. The vast majority of colorectal cancer patients visiting outpatient clinics attend for routine follow-up appointments that normally involve a brief consultation with an oncologist. According to some clinicians this task could be performed equally effectively by a qualified nurse.

A further way in which some oncologists have started to contain their workload is through earlier discharge of patients. Whereas previously most patients were monitored on a regular basis by an oncologist following their treatment, currently they are being discharged back to the care of

their surgeon or GP. Whether patients could benefit more with regular visits to the oncologist is unclear. However, the Calman-Hine report recommends that follow-up should be carried out by a multidisciplinary team of specialists and primary health care workers (Calman-Hine, 1995). Certainly, one official responsible for commissioning cancer services at Avon Health Authority claimed that GP follow-up can be as effective as hospital follow-up for many cancers.

Dr Davis. Looking at the evidence, GP follow-up for breast cancer is equally good to hospital follow-up. I mean what's the purpose of follow-up anyway. Are you really trying to find recurrences early, in which case it's the patient who'll find them and the GP who usually diagnoses them. And the most important thing is that the patients are handed back properly (Interview 46, p9).

However, this statement says nothing about the need to provide an adequate continuity of information to patients, and it is debatable whether primary care teams have the necessary expertise to provide relevant information to patients during various stages of their illness.

Avon Health Authority is trying to encourage certain procedures to be performed in the primary care sector in order to ease the burden on hospitals. One analysis of the purchasing plans of all the health authorities in England and Wales for 1996/1997 has shown that services are increasingly being devolved to primary health care teams (Redmayne, 1996). One of the ways in which this is being carried out is through the appointment of specialist nurses working in the primary sector with a responsibility for the care of patients in a wide range of areas including cancer care. For instance, West Kent Health Commissioning Agency is developing schemes in general practice to involve nurse practitioners in the care of patients who are 'high-attendees' or who have long-term and chronic health care needs.

The degree to which such policies encourage earlier discharge from hospital, and will result in costs being shifted from the secondary sector to primary care, has been debated in the literature. Morgan and Beech (1990) cite several studies that compared the health outcomes of patients attending day case and inpatient stays for the treatment of haemorrhoid and inguinal hernia repairs. The studies found that although there were no differences in clinical outcome between day case and inpatient surgery, day case patients required 4.18 more visits from district nurses and 0.5 more visits from GPs. This indicates that although earlier discharge of patients undergoing certain procedures may reduce hospital costs per patient treated, it also may result in 'knock-on' effects for community services such as district nurses and general practices.

According to Avon Health Authority, who is the main purchaser of cancer services from Bristol Oncology Centre, there are certain safeguards, which prevent excessive costs being transferred from the secondary to the primary sector. For instance, a Prescribing and Therapeutics Committee, which has wide representation from hospital clinicians and GPs, has been set up to

monitor the cost of prescription drugs. Any new drugs that show marginal effectiveness will not be recommended for use. Thus, GPs who have a limited budget will not be expected to prescribe drugs, which they cannot afford. However, such a policy may only have a limited impact in preventing the financial burden of care being transferred to the community if hospitals choose to discharge patients earlier.

Further evidence of cost shifting emerges from a few recent randomised controlled studies comparing hospital at home care with inpatient hospital care. Shepperd et al (1998a, 1998b) found that the total healthcare costs of 'hospital at home' were greater than hospital care for elderly medical patients and those with chronic obstructive airways disease. Coast et al (1998), also found in their study of hospital at home versus acute hospital care, that costs for general practitioners of hospital at home care increased slightly. These studies indicate that although early discharge of patients with acute medical conditions lifts the burden from the secondary services somewhat, there is some indication that the total cost of providing these services is not so much reduced, as shifted, to the primary sector.

The emphasis on primary care

The Expert Advisory Group have recommended that stronger links should be established between primary care and secondary care services in the treatment and diagnosis of cancer (Calman-Hine, 1995). Whereas previously the transfer of cancer patients between primary and secondary care tended to be very abrupt, the emphasis is now more on better continuity of care. In particular, the report states that discharge information should reach GPs on the day of discharge, and any changes in patient management should be made known to all those involved in the care of patients. The Expert Advisory Group have also suggested that cancer services should be concentrated in specialist cancer centres and units which will develop expertise through treating large numbers of patients.

According to Grmfeld et al (1995) one of the tasks which could be carried out by primary health care teams is follow-up care. According to the authors, the difficulties of following up breast cancer patients in breast clinics are especially acute due to the large numbers involved. This situation is set to worsen as breast cancers are detected at an earlier stage through the national screening programme. This will place a greater strain on already over-stretched cancer services. In addition, the demands of follow-up may further limit the time available for newly referred patients who need more urgent specialist attention.

Some Health Authorities such as Sunderland Health Authority are encouraging primary care teams to diagnose and treat the vast majority of problems, as well as provide palliative care. It is also its intention that primary care workers will share responsibility for patients and take them back as quickly as possible following their treatment in hospital (Redmayne, 1995). One oncologist at Bristol Oncology Centre suggests that a similar pattern is occurring in oncology.

Dr Harris. This is a consultant led service, so patients tend to see mostly the same doctor each time they come for treatment, and we try to follow-up patients as far as we can. But there is an emphasis to transfer as much follow-up as possible to general practitioners. We can maintain some continuity through communication with GPs and there's an open door, that if there's a problem they can send the patient back. That's how we're trying to achieve it, rather than hanging onto patients ourselves (Interview 39, p12).

Avon Health Authority has also been trying to encourage the greater involvement of primary health care teams in the management of cancer. One official responsible for commissioning cancer services at Avon Health Authority has stipulated that GPs can offer patients an important information and monitoring service following their discharge from hospital.

Dr Davis. One standard I'd like to see is that every patient has it explained to them in a kindly way by their practice that even though they're going to hospital there's still a lot that the practice can offer them. Because they tend to lose touch with their general practice, and it's all sort of seen as very technical, and then suddenly the family are having problems and the pain control isn't good, and the poor GP gets called in at eleven o'clock at night and he's completely lost touch with what's happened (Interview 46, p9).

The need for hospital consultants to involve community health services as a matter of course appears to be high on the agenda for Avon Health Authority. Better liaison and communication between hospital services and GP practices will improve the care which patients receive. Avon Health Authority are also trying to change the current ethos of cancer therapy which currently places a high emphasis on consultant led care. The need to encourage a multidisciplinary approach in the management of cancer is becoming much more important. This new emphasis is recommended by the Expert Advisory Group on cancer, which suggests that the cancer unit should be integrated with the primary care sector, multidisciplinary palliative care services, and rehabilitation services.

The Advisory Group report also strongly recommends the need for clear routes of liaison and referral to palliative care and rehabilitation services. Currently, there is a tendency for oncologists

to place greater importance on high technology therapy such as chemotherapy and radiotherapy, without informing patients of the care and treatment which can also be offered to them outside of the hospital sector. For instance, Dr Davis argued the following.

Dr Davis. There is a tendency for a hospital based oncologist to completely dismiss and under value the therapeutic impact of saying to people "we will go on looking after you in conjunction with the palliative care team and with your GP and district nurses. There will be skilled people there to support you and your family. There will be pain relief, there will be symptom control". And I still feel, not all but some oncologists have this kind of like, if you stopped active treatment that's it, which is very depressing, and the GPs speak very vociferously about how sometimes chemotherapy is just carried on to the nth degree and then palliative care people get involved at the eleven and a half hour, and what can you then do when the family haven't even prepared themselves for the fact that death is inevitable (Interview 46, p7).

Although many health authorities in the United Kingdom are shifting the emphasis of care to the community and trying to secure a better continuity of care for patients across all specialties, this does not mean that such initiatives are problem free. Grunfeld et al (1995) observed in their study investigating the views of GPs, specialists and patients towards routine follow-up of breast cancer, that several important issues must be addressed before the care of cancer patients is transferred to the primary sector. They found that it is still unclear whether GPs possess the appropriate skills to detect recurrences in patients with irradiated breasts, and whether adequate psychosocial support can be provided in the primary sector. The GPs who were interviewed in the study also expressed concerns about the danger of inheriting large list sizes and receiving inadequate compensation for the increasing workload.

Crump et al (1995) further state that as fund holders, general practitioners might not welcome the total clinical responsibility for patients who receive high cost treatments, because their concerns about prescribing for such patients involve more than just money. In the presence of cost shifting practices to the primary care sector, the pressure is taken off the consultant who will in effect have open access to the GPs budget. In addition, the full costs of expensive treatments may not be reflected in the costs of contracts placed by purchasers if the costs of the treatments are transferred to the practitioners. As a result, purchasers may be more willing to contract for such services, which will then lead to a knock on effect for general practitioners who may limit the care available due to financial pressures.

This concern is echoed by some health authorities in the UK who lack additional resources to fund the transfer of care from the secondary to the primary sector (Redmayne, 1996). Also, some purchasers are discovering that for certain conditions, devolving care to the community does not necessarily mean a reduction in demand in the secondary sector. For instance, East Lancashire

Health Authority has found that the growth in minor surgery carried out by GPs has not resulted in a corresponding decline in hospital activity. Similarly, the increasing pattern of early discharge of cancer patients from the Bristol Oncology Centre could mean that the responsibility for their follow-up is carried out by surgeons or GPs. However, it is unlikely that such initiatives will reduce the total number of patients being referred to the Oncology Centre due to the national screening programmes (cervical and breast cancer in particular). This is because patients are presenting much earlier to their GP, perhaps placing more pressure on them to refer (Ashby et al, 1990), and because improved access to primary care may result in the identification of previously unrecognised morbidity (Redmayne, 1995).

Referral practices of surgeons

The other important factor that may determine the numbers and types of patients referred to an oncologist is the referral practices of surgeons. As mentioned previously, the colorectal cancer patients who are referred to the Bristol Oncology Centre tend to have more advanced disease for whom treatment is of proven benefit. Patients with earlier disease are less common because the incidence of colorectal cancer at the time of presentation tends to be of a more advanced nature, and because oncological treatment for early disease has not been shown to provide any additional benefit in terms of survival. As a result patients with early disease are often not referred to an oncologist. Thus, many patients who are referred to the Oncology Centre tend to have more challenging conditions, which means that the cost of treatment could escalate as referrals increase.

Another difficulty is that there are wide geographical variations in the referral patterns of surgeons. These referral patterns are often determined by the population characteristics of a particular area, the existence of specialist cancer centres, the allocation of resources, and the purchasing practices of health authorities (Harding et al, 1993; Dillner, 1995). Thus, the centralisation of cancer services within a Cancer Centre is likely to encourage referral from surgeons in the future. This means that even if cancer care is devolved to primary care, it seems unlikely that this will reduce the demand placed on oncological services. Indeed, a Briefing Paper (1996) produced by Avon Health Authority, regarding the Bristol Oncology Centre, stated that the cost pressures inherent in treating cancer patients are a permanent fixture of the present day health service. Mainly, the rising costs are due to the emergence of expensive new experimental drugs.

In view of the observation that cancer centres will probably attract greater demands on their services, oncologists may find it difficult to dedicate sufficient time to patients. Oncologists may not be able to actively encourage patients to participate in the decision-making task, and perhaps greater pressure will be placed on patients to make treatment decisions quickly and with insufficient guidance from the oncologist due to time constraints.

Contracting practices

The Expert Advisory Group has asserted the need for providers to account for the management of different diseases, and the detailed needs of particular groups of patients. Currently, in most contracts many services and service costs are not identifiable because they form part of more general contracts, such as for general surgery. Thus, the Calman-Hine recommendations advocate a system under which contracts should be developed to cover each individual cancer site. This would provide more accurate data on the utilisation of resources and costs incurred by individual services, which would hopefully lead to a more effective system of resource allocation. Whitehouse (1995) argues, however, that a greater focus on contracts which are specific for each cancer site will fragment the purchasing process as well as the provision of care by shifting the emphasis on individual cancers rather than providing an integrated service to all patients. A similar view is shared by the clinical director of oncology at the Bristol Oncology Centre who suggests that a change in the system of contracting and the introduction of clinical guidelines will have practical implications for the management of patients. For instance, contracting according to individual cancer site does not account for individual patient variability and complexity inherent in the daily tasks of treating patients. Cancer services are interdependent and to a certain degree costs are shared between the sub-specialities.

Dr Harris. I think it's important that we should make use of the evidence that's available, but in the end it only gives you a guideline. It doesn't give you an exact way of treating every patient. It's up to the individual doctor to talk to every patient, and with those guidelines and the experience that he's had to advise and get an agreement with the patient as to what's best for that patient. So that we may have a policy that patients with early breast cancer should be entered into adjuvant chemotherapy trials, but some patients may not want to go into trials, some patients may not want to have chemotherapy. Rather than have rigid rules, we try to have protocols which are sufficiently flexible to allow for individual variation (Interview 39, p5).

The recommendations which the Chief Medical Officers' Expert Advisory Group puts forward may lead to very rigid costing practices, since the cost of services will be calculated on an individual basis rather than within the wider context of cancer care. Such a system may result in under funding and the fragmentation of services. The Bristol Oncology Centre is responding to this government initiative with a compromise, by developing its own contracting strategy that is more sensitive to service and treatment costs. The clinical director illustrates one way in which this is currently being achieved.

Dr Harris. To some extent the hospital administration management has been set up to cater for the more common specialities-general surgery, general medicine. So contracting is not sensitive to the wide variations of treatment and cost that we have here. It's more based on cold surgery and hospital admissions. And therefore we're having to develop our own ways of contracting and hoping to use fewer health resources, so that you bundle procedures together perhaps into groups of four or five, depending on how much resources they use, you know, the very expensive ones or the very cheap ones. It doesn't matter if your treating a rodent ulcer or a painful metastasis for breast cancer. If that's cheap, it comes in the cheap box. At the moment purchasers are not geared up to do that (Interview 39, p8).

Indeed, another consultant oncologist indicated the same problem that contracting practices of health authorities are not sensitive enough to the cost of care in real terms.

Dr Hutton. Increasingly, purchasers are not going to accept everything that doesn't have some evidence behind it. I think there's an irony that they're only interested in things that cost a lot. We do many things that don't cost a lot per patient but if you add it up...(Interview 44, p8).

Although Contracting on the basis of individual cancer site may be beneficial for purchasers in their bids to achieve greater cost-effectiveness, as the expenditure of each sub-speciality will be monitored more closely. However, such a system needs to maintain some degree of flexibility. The system under which a health authority commissions services using a 'block' contract, where a set amount of revenue is given to a particular speciality for its services, is currently deficient. Such a system is insensitive to the wide variations in cost and treatment particular to units such as the Oncology Centre, because contracting is based on 'cold surgery' and 'hospital admissions' which are poor indicators of hospital activity on their own. According to the clinical director of the Bristol Oncology Centre, a good compromise might be a system that is based on the use of

resources as it can at least take into account the overall cost of services. However, the strategies used by purchasers are currently not sophisticated enough to contract on the basis of cost or cancer site. One of the major reasons for this is the lack of information and audit in cancer care. A theme I shall turn to subsequently.

Cost effectiveness

The purchasing plans of most health authorities in the UK have emphasised the need to pay particular attention to the clinical effectiveness of treatments and services (Redmayne, 1995). Procedures that have been shown to be ineffective are usually scaled down or not purchased by health authorities. On the other hand, some purchasers are more willing to buy services that are proven to be effective. Due to rising costs Avon Health Authority has increased its level of scrutiny of cancer services by requesting evidence of clinical effectiveness before any additional funding is approved. The Bristol Oncology Centre has responded to the pressures on them to provide evidence of the clinical effectiveness of each service that they provide. Certainly, the rising cost of cancer treatment has made it inevitable that oncological services will need to be audited and monitored more closely than before. The clinical director of oncology in Bristol indicates how this might be achieved.

Dr Harris. I am aware that there are a number of patients who don't benefit from palliative chemotherapy and yet receive it....and two out of three people get the side effects and no benefit. We're looking at everything much more critically in terms of the benefits to individual patients, and also auditing more carefully what our experience is here. We need to check if we're getting them, and if not, why not. And is our patient selection different, and are we treating patients inappropriately (Interview 39, p9).

One area which has been subjected to greater scrutiny than previously is palliative treatment. Palliative services are highly expensive and providers are seeking ways of scaling down the numbers of patients that they treat. The Bristol Oncology Centre has audited palliative chemotherapy for colorectal cancer and found that many patients are treated inappropriately. As a result purchasers may be less willing to contract for palliative treatment which has not been shown to be effective, resulting in a decrease in the level of hospital based palliative chemotherapy. The clinical director illustrates this point.

Dr Harris. The decisions on the treatment at a higher level are taken by the health authority, in terms of what they regard as their priorities. Avon have many demands on their resources and essentially insufficient money for the service. We're looking very carefully at what they are willing to purchase. It's becoming increasingly difficult for us to provide what we regard as a basic service within the resources (Interview 39, p3).

It is evident, therefore, that providers are increasingly faced with the need to take into account what services and treatments purchasers are willing to contract for. The whole issue of whether to provide a service on the basis of patient 'demand' is being subjected to re-evaluation. It looks increasingly likely that the provision of services will depend on whether providers are able to demonstrate not only the clinical effectiveness of treatment, but also its cost-effectiveness. Thus, the concept of 'need' may progressively become subjected to an economic definition in decisions that are concerned with the use of resources.

The National Association of Health Authorities and Trusts indicate in their research paper on purchasing policies in the NHS, that most health authorities are purchasing interventions and services that are demonstrably effective and provide the most health gain (Redmayne, 1996). Avon Health Authority is attempting to develop a purchasing strategy that not only encourages effective services, but one that seeks to end services that are not effective. For instance, it wishes to encourage and support clinicians in actually stopping some of the less effective services that they currently provide. Palliative chemotherapy for certain patient groups is the obvious candidate. Also, it wants to encourage Trusts, GPs, and hospital clinicians to contemplate cuts in other services and to consult honestly with the public over the need to prioritise and redirect funding (Briefing Paper for the Executive Team, Avon Health Authority, 1996).

In addition, the Briefing Paper explicitly states that it wants to resist the introduction of new cancer screening programmes, such as those for prostate and colorectal cancer. These programmes could cost £10 million per year in Avon and benefit very few people due to the anticipated low detection rate. In conclusion, Avon Health Authority's purchasing policy emphasises the need for treatments to demonstrate their cost effectiveness before resources are provided to subsidise them. Purchasing decisions for certain types of treatment, however, present somewhat of a challenge to health authorities especially in cases where their effectiveness is ambiguous.

Establishing equitable service delivery

One of the pressures faced by purchasers, as well as hospital consultants, is the need to make decisions about treatments that may be regarded as 'inappropriate' or at the margins of mainstream medicine. Not only is the information required for making such decisions often unavailable or incomplete, it usually involves making value judgements between different health care needs and services. One way in which health authorities are dealing with this problem is to give low priority to high cost procedures which produce limited health gain, interventions of unproven effectiveness, and services which are not essential to health gain such as tattoo removal (Klein, 1995).

One case illustrating the difficult decisions which sometimes need to be made regarding expensive cancer treatment, is that of Helen Bourton who was denied palliative chemotherapy treatment (Taxol) because Avon Health Authority did not regard it as a priority in their spending plans. Indeed, the director of Oncology at Bristol Oncology Centre stated in 1996 that certain regimens of palliative chemotherapy which are effective but high cost are not offered to patients. He claimed that in response to the increasing demands on oncological services certain constraints have to be made in terms of the service that is provided.

Dr Harris. We had to make some constraints on what we do. So far limitations have been implicit. We don't offer Taxol chemotherapy as that's too expensive and we don't offer others. We don't offer as much palliative chemotherapy as some other centres which are perhaps better funded, and we could regard that as perhaps not providing as good a service as we should (Interview 39, p7).

As this interview passage demonstrates palliative chemotherapy has been subject to constraints due to budget limitations, and these decisions have largely been implicit. This means that patients are actually not offered certain treatments by their oncologists on grounds of cost even though the decision-making task is considered to be a clinical matter rather than an economic one.

Helen Bourton underwent surgery to remove her tumour, she had first-line chemotherapy and radiotherapy, she relapsed and then she had a second course of chemotherapy treatment. She was told that her condition was terminal. Although, she heard about 'Taxol', which the oncologist was unable to offer as it was not available on the NHS. The issue of equitable provision of treatments was raised because 'Taxol' was available to patients in other neighbouring districts but not in Bristol. With reference to the 'new scientism' in the health care system, Klein et al (1996) highlight the importance that decision-makers address important dilemmas. Including whether or not to spend large sums of money on individual lives rather than on less visible and 'dramatic'

services. Avon Health Authority have argued that although the media tends to draw attention to geographical inequities in access to health care, it overlooks the wider context within which services are provided. For instance, an official at Avon Health claimed that the media draws public attention to such issues, because they are very easy to understand and tend to evoke an emotional response. However, the overall care that is delivered to cancer patients in Bristol may be much better than that provided in other districts despite the unavailability of a certain cancer drug.

Dr Davis. We're constantly feeling that we're being pressured to spend on very visible things...because they're very simple and easy to understand - that woman A gets drug because she lives that side of the boundary and woman B doesn't if she's the other side. But it's very hard to actually say but look the whole standard of care, she's not being seen by a multidisciplinary team there, there's no link with a hospice down there, the district nurses are thin on the ground down there, whereas all those things are good here...And to us the cancer service is far more than whether you get a drug or not (Interview 46, p4).

The Helen Bourton case also emphasised the increasing tendency of purchasers to subscribe to the 'utilitarian' principle in its overall resource allocation strategy, by ensuring that the resources are allocated to the catchment population in a way which ensures that every eligible patient receives an equal service. Thus, avoiding the likelihood that a greater share of the resources are spent on more 'deserving' or 'special' cases. Klein et al (1996) have stressed that clinical discretion in deciding why one person receives treatment and another does not, may hide the uncertainty and arbitrariness in decision-making, and the resources may go to the most persuasive patients. Thus, a more open and explicit approach to decision-making may encourage more equitable access to health care. Klein et al (1996) claim that:

...many of the choices that are made cannot be described as 'tragic'. Indeed, by concentrating on dramatic examples of decisions involving matters of life and death we risk distorting priorities by ignoring those services which provide care for those who cannot be cured....Services with low visibility are likely to get low priority: hence the case for providing the contextual information required to compare different claims on resources (Klein et al, 1996, p43).

One official involved in purchasing cancer services at Avon Health Authority expressed a similar concern:

Dr Davis. I mean there's nothing worse than the kind of hysterical

communication we have sometimes with patient pressure groups because they don't acknowledge, they just say well you've got to buy hope. But when you say how do we as a health authority balance cardiac services versus orthopaedic versus oncology versus care for children with disabilities. The answer is we try and do our best, but the thing that really worries me is that services which are less visible like support for parents who have got severely disabled children, that's atrocious and it's very hard to articulate that or get it seen as a priority (Interview 46, p7).

The research paper published by the National Association of Health Authorities and Trusts concluded from its analysis of 66 purchasing authorities in the UK, that equity and access were the main guiding principles of health service provision (Redmayne, 1996). The majority of the strategy documents included equality of access and the need for more equitable services as the main planning objectives for the future. Certainly the greater emphasis on primary care suggests that purchasers want to move health services nearer to the consumer and achieve more equal access this way. One fundamental reason why health authorities have been limited in their ability to assess existing service provision and local needs is the lack of good audit data (Redmayne, 1995).

Rationing through the use of clinical protocols

Health authorities are facing the difficult task of deciding on how best to make the most cost-effective use of resources without having to make explicit rationing decisions. Most rationing decisions in the NHS are implicit, and purchasers have been careful to limit public controversy by assigning low priority to certain treatments rather than by explicitly excluding them. The difficulty for most purchasers lies in ensuring the 'appropriate' use of health care resources. However, the definition of 'appropriateness' is highly ambiguous and cannot be simply based on definitions of clinical effectiveness since most treatments will be effective on some patients but may not necessarily be appropriate (Redmayne, 1995). What many health authorities tend to do is to disguise most rationing decisions as clinical decision-making by defining 'appropriateness' as a medical issue. The development of clinical protocols and guidelines as the best means of ensuring that health care resources are being used appropriately is increasing.

If purchasers decide to exclude certain procedures or limit the funds available they place the ultimate responsibility for determining the treatment of patients on clinicians themselves (Klein et al, 1996). Thus, purchasers have avoided potential conflict with the medical profession by

deciding to allow doctors to make the decisions relating to the clinical selection and management of patients, whilst at the same time averting any public controversy. As Klein et al (1996) indicate, services are not struck off the NHS menu but rather given low priority in resource allocation. Thus, clinicians become responsible for the use of those resources according to their criteria of 'appropriateness', offering a new legitimisation of selectivity.

Avon Health Authority has been developing clinical guidelines closely with Bristol Oncology Centre as a means of maximising resource use. Indeed, one official at Avon Health indicated that the development of quality standards is their main priority in ensuring a good service.

Dr Davis. Intuitively I feel it's better to go on quality standards so if you can see that the quality standards are all being met, that means more to me than knowing that this amount of money went on that service, and it's getting the quality standards so that they are robust and you can measure them without loads of extra work (Interview 46, p12).

Thus, what is important for Avon Health is the need to ensure that resources are spent most appropriately and that quality standards are maintained. A collaboration between seven Trusts and three health authorities has been set up in Avon (Avon and Somerset Cancer Services Collaboration) in order to set standards for the care of different cancers and to monitor the services which are offered to patients. Avon Health Authority has clearly played an important part in defining the standards of cancer care closely with Bristol Oncology Centre, rather than leaving the task completely to the clinicians (Briefing Paper for the Executive Team, Avon Health Authority, 1996). There is also some evidence to suggest that Avon Health Authority are moving in the direction of greater explicitness in their resource allocation decisions. For instance, with regards to 'Taxol' which is a breast cancer chemotherapy drug with evidence of benefit for patients with advanced disease, Avon Health Authority has decided to be more 'open'. Through closer collaboration with Bristol Oncology Centre, Avon Health have refrained from leaving clinicians to decide alone whether certain drugs should be offered to patients. In a letter to the Secretary of State for Health regarding the Helen Bourton case, Avon Health Authority confirmed their move towards greater 'explicitness' in resource allocation decisions.

Dr Davis. So far as we are aware, however, no Health Authority has taken a positive decision to invest identified new money to cover the full costs of Taxol use for every patient with advanced breast cancer who might benefit. Some Health Authorities say "we are leaving it to the clinicians". Some endorse its use for individual named patients. Our view is that this is something of a fudge. If Taxol use is absolutely the highest priority of all the possible new investments that could be made for health services in Bristol then we should say so and try and find the money for it. If it is not the highest priority then we should be prepared

to acknowledge the fact. Our cancer specialists are facing an impossible situation knowing that treatments exist which could bring a slim chance of benefit for many patients. Do they tell patients about them? Or do they keep quiet? (Interview 46, p12).

It is evident that Avon Health believes that sometimes hard choices have to be made, and when purchasers leave these difficult decisions to individual doctors what they are doing in effect is diverting such decisions without resolving the underlying issues. The Bristol Oncology Centre is facing increasing pressure from articulate and well motivated patients to receive funding for expensive treatments, which is why Avon Health Authority has decided to work in partnership with oncologists in setting priorities and defining the principles on which service provision should be based (Briefing Paper for the Executive Team, Avon Health Authority, 1996). Indeed, many purchasers have set up clinical effectiveness forums to evaluate the available evidence about various procedures with clinicians and GPs. Other health authorities in the UK are also involved in developing protocols which can control the use of services and treatments so that service utilisation can be targeted most appropriately (Redmayne, 1996).

Most health authorities are faced with the difficult dilemma of setting priorities for treatments and guidelines to shape those priorities on the one hand, and the need to allow for some level of flexibility in clinical decision-making. For instance, the clinical director of oncology at Bristol Oncology Centre stated that management protocols need to allow clinicians some room for manoeuvre and individual variation.

Dr Harris. We're in the process of preparing information for the purchasers so they can discuss with us what the priorities should be. At the moment we're exceeding our budget. The Trust tells us that is not something we can do. We'll have to draw back somewhere, and we need to discuss with the purchasers what will cause the least harm to patients. I think it's important that we should make use of the evidence that's available, but in the end it only gives you a guideline. It doesn't give you an exact way of treating every patient. It's up to the individual doctor to talk to every patient and within those guidelines and the experience that he's had, to advise and get an agreement with the patient as to what's best for the patient (Interview 39, p8).

This narrative illustrates the point that even though purchasers may be involved in the development of clinical guidelines with clinicians as a means of controlling expenditure and maintaining high standards of care, doctors are considered to be the ones who should decide which patients receive treatment. Thus, although low priority may be assigned to a certain treatment the decision to offer or not to offer treatment, is usually made by the doctor, in effect, perpetuating a system of implicit rationing.

Klein (1995) has argued that using explicit criteria in setting priorities is very difficult to achieve. He claims that the allocation of resources, based purely on an economic appraisal of the costs and benefits of care needs to be avoided if health care is to be targeted to patients on a personalised level. He claims, with reference to the difficulties inherent in implementing decisions based on standardised guidelines, that rationing should be open to some interpretation or 'dilution' by clinicians.

The devil lies in translating general principles into practice, particularly when it comes to the treatment of individual patients. There is a case, therefore, for pragmatism-that is, for distilling general rules from practice rather than imposing a set of principles on practice (1995, p762).

However, he concludes that the question of implicit versus explicit rationing cannot be conclusively resolved, since changing social attitudes and new medical technologies will continue to create novel dilemmas in the decision-making process which neither science nor economics can resolve (Klein et al 1996).

Conclusion

The escalating cost pressures that cancer services are currently experiencing have resulted in policy initiatives to streamline the delivery of care as a result of the Expert Advisory Group recommendations, which seek to centralise cancer services whilst placing more responsibility on primary care. A review of some of the research evidence suggests that concentrating much of the care in the community that traditionally had been carried out in hospitals may shift costs to the primary health sector rather than making real savings in secondary care. Further, the initiative to provide various services for cancer patients in the community raises the question of whether GPs and other health care workers possess the technical competence to provide such care. For instance, some doubt has been expressed over the availability of appropriate psychological support for patients in the community.

Much of the debate on current policy in the NHS emphasises the fact that decisions to prioritise services will present purchasers with difficult dilemmas which science nor economics will resolve entirely. Although scientific information will show whether a treatment or a procedure is effective, it will not offer a formula to show which service should be given greater priority because such decisions require a value judgement. The administrative effort required to

implement any new policy usually leads to additional costs, and the Calman-Hine recommendations have not been met with extra funding since the policy is essentially an initiative to reorganise existing cancer services. The financial consequences of such a policy are likely to be significant, and some of the possible implications have already been discussed. For instance, the likely changes to the contracting practices of providers and purchasers will continue to impose strict checks on service delivery through the wider use of clinical protocols and via a greater emphasis on clinical effectiveness. The danger that the costs incurred by providers will be shifted towards primary care teams is very real, and one which cannot be resolved with ease, according to the above analysis. Since one of the aims of the Calman-Hine recommendations was to identify and treat more cancer patients effectively without the need to provide additional revenue, the knock-on effects on other areas of the NHS could be significant. For instance, GPs may be less willing to refer patients with longer-term chronic conditions to specialist units in the fear that they will inherit much of the financial pressure previously felt by the secondary sector.

CHAPTER 7

RESULTS AND INTERPRETATION

I. Patients' perceptions of decision-making in cancer treatment

Introduction

One of the most significant changes to take place in the doctor-patient relationship in recent years is the increasing endorsement of the principle of 'informed-choice'. This postulates that patients should be well informed prior to consenting to treatment, and that they should have enough information to empower them to make an informed treatment choice (Kessel, 1994; Wagner et al, 1995). The growing pressure placed on doctors to provide treatment choice to cancer patients, alongside the increasing use of scientific evidence to guide decision-making, can potentially lead to conflict between the oncologist and the patient. This is because patients may make choices which clinicians may consider to be 'irrational' (Brock and Wartman, 1990). The extent to which conflict does actually take place is examined during the course of this chapter. In addition, the impact of the doctor-patient relationship on the decision-making task is assessed.

Several models of the doctor-patient relationship have been devised in recent years to reflect on styles of interaction within the context of a changing health service, in which patients are becoming increasingly vociferous and demanding (Szasz and Hollander, 1956; Henbest and Stewart, 1990; Delbanco, 1992; Botelho, 1992; Laine and Davidoff, 1996; Deber, 1994). Some studies have linked greater patient involvement in decision-making to better psychological and physical outcomes, whereby patients often profit from maintaining some control over the management of their illness (Taylor, 1985; Fallowfield, 1990; Biley, 1992). Other studies have advocated greater patient participation in decision-making to ensure that patient preferences are consistent with the decisions that are reached (Charles et al, 1998). Thus, the case for a greater

degree of involvement of patients within the doctor-patient relationship is gaining strength. Throughout this chapter, these issues are explored further with reference to the study results.

Within this chapter, several related issues are explored: (1) the ways in which individuals with colorectal cancer perceive the risks and benefits associated with their illness and treatment; (2) the degree to which they believe that they have a treatment choice; (3) the roles they prefer for themselves, and for their oncologists in the decision-making process; (4) the type of information which they desire from their specialist; (5) and the roles patients and oncologists actually play within the consultation.

Presentation of the Data

Pseudonyms are used to hide the identity of the interview informants. Throughout this chapter the interview excerpts and the observation narratives are supported with background information about disease stage and type, marital status, occupation and age of the informants and patients. Further background information, such as ethnic group, is provided where it is available or relevant. The interview quotations and observation excerpts that are used in this chapter have been selected because they are representative of the theme or themes that they are describing. Some informants are quoted more than twice because their responses encompass succinctly and accurately the particular theme of interest. They also are used because they are representative of the responses describing a certain theme. During the interviews some informants were more articulate in communicating the message that they wanted to relay. Less articulate informants sometimes communicated their message in a way that would have made it difficult to demonstrate clearly with quotes. For this reason certain informants are quoted more often than others. However, the responses of all the informants have been included in the analysis. Numerical counts are provided for each quotation and consultation dialogue in order to demonstrate the representativeness of the theme in question.

Identity of doctors

There were five oncologists who led the consultations during the study period: a male lead consultant in clinical oncology (Dr Tom Fenton) and a female senior registrar in clinical oncology (Dr Anne Smith). However, 10 consultations were also conducted by a male Professor in clinical oncology during the study period (Dr Mark Hutton) and two female registrars in clinical oncology (Dr Jane Richards and Dr Victoria Bench). These five oncologists formed the basis of all the consultations that were conducted during the course of the study.

Responses to risk and benefit in decision-making

Risk perceptions

Although much is written about the increasing use of scientific evidence in medical practice by clinicians, very little is known about how this new style of medicine affects the patient. One recurrent theme in this study indicates that colorectal cancer patients experience some degree of uncertainty about the benefit of treatment. This uncertainty is not at all surprising given that in most cases the course of a patient's disease is difficult to predict. This section will demonstrate how the interview informants responded to and interpreted the uncertainty surrounding treatment benefit following their first contact with the oncologist.

In a study of childhood leukaemia, Camaroff and Maguire (1981) found that parents of child sufferers could only come to terms with the uncertain 'behaviour' of the disease by maintaining a strong sense of hope and optimism even when the odds were stacked against them. For example, the author claims that,

the hope of long term remission becomes the preoccupation of all families, despite their awareness that the odds are unfavourable; and this hope is poignantly maintained against counter evidence (p116).

The families of the afflicted children in this study were aware that the cancer could return at any time. Nevertheless, they maintained a strong sense of optimism as a way of coping with their child's illness. The tendency of families to maintain hope of long-term remission in the face of

counter evidence reflects the coping strategies employed by many informants in the current study. The only difference being that the families in Camaroff and Maguire's (1981) study were aware that remission was not long-term. In contrast, informants in the current study often believed that with the help of treatment, remission could be long term. However, the most interesting observation made from the interviews was the tendency of informants to translate the information that they were given by the clinician in an optimistic way, even when it was communicated by the oncologist in a less 'positive' manner. The following dialogue from a consultation between David, a 64 year old man with advanced colorectal cancer, and Dr Fenton (consultant clinical oncologist), demonstrates how 'bad' news was communicated to a patient. This is defined as a situation where the oncologist discloses a poor prognosis or notifies the patient that the disease is too advanced for treatment to be effective. 'Bad' news was communicated by the oncologist in 10 out of the 55 consultations that were observed.

Dr Fenton. What do you understand by what's happened to you and why you are here today?

David. Cancer of the bowel. They cut it out but there are small bits which are too small to cut out, so I've come for chemotherapy.

Dr Fenton. The news isn't terribly good I'm afraid. The cancer spread to the lining of the tummy. These little spots are terribly hard to identify. So whenever that happens we think about what's available. The problem with radiotherapy is that the total dose we can give is very small. We do use radiotherapy quite a lot but it won't alter the course of the disease. Alternatively, we give chemotherapy. We use it in two situations: where we can't see cancer cells and where there are deposits where we can see. In the latter case it's very unusual for chemo to provide a cure. It only works for one in three patients. For one third of patients it shrinks the tumour. The side effects can be adverse, and you'll have to make up your mind whether it's worth it. Skin rashes, diarrhea..... We want to put you over a body scanner, so we can give you three months (of the chemo) and then we can decide whether to continue. The scan doesn't usually show up well. It's a very difficult decision. It's a very serious situation.

David. With me personally?

Dr Fenton. Yes.

David. How long have I got?

Dr Fenton. I'm afraid I cannot say, but the chances of you being cured are very low. Some people survive for years, others not. If the treatment works well you could have further treatment (Observation 24, p1).

(Duke's D colon cancer, married, local government officer, 64)

The oncologist is preparing the patient for the fact that his cancer is incurable and that death could be imminent. The oncologist does not provide much hope that the patient will recover from his illness. Indeed, he informs David that oncological treatment is unlikely to work. However, subsequently at the interview David still felt somewhat optimistic that treatment would at least prolong his life.

David: I didn't fancy not having it and finding out that I would die quickly, die in pain without any treatment at all. Otherwise if you hadn't chosen the chemotherapy you'd be sent home and sort of left to die you might say. You might not have much treatment afterwards (Interview 35, p7).

(Duke's D Colon cancer, married, local government officer, 64)

This response is typical of the views expressed by informants in the interviews as a whole. In 23 out of the 37 interviews informants expressed at least some degree of optimism that the treatment would benefit them in their recovery. Most of the 14 informants who did not express the same level of 'optimism' (at the initial interview) regarding their illness, tended to have more advanced disease. They were aware of their poor prognosis, and most were not receiving any treatment because of the advanced nature of their illness.

David also felt that accepting the treatment option enabled him to feel that something positive was being done about his condition even if cure was unlikely. If he refused the chemotherapy he would feel abandoned by the medical system. Thus, his desire to accept treatment was a reflection of his need to maintain a 'fighting' spirit. Even though the oncologist warned that chemotherapy might not help his recovery, David still wanted to undertake the treatment option as a way of hanging onto the hope that the treatment might prolong his life. In addition, the fear that future treatment might be unavailable if the current opportunity to undergo therapy was missed, was a further concern for the informant. Thus, the risk of having treatment outweighed the risks of refusing chemotherapy for David.

It is significant that many informants felt the need to interpret an uncertain situation in terms of a positive outcome. The informants in this study indicated that they coped with the uncertainty of their cancer prognosis with attempts to minimise it. This was often done in one of two ways: informants either interpreted risk related information in a positive manner, where they claimed that treatment would help to minimise that risk; or they associated further treatment with a greater confidence that something was being done about their illness. Although sometimes the information that was communicated by oncologists in this study tended to be portrayed in an

'inconclusive' way, it is interesting how many informants construed this uncertainty in terms of a positive outcome for themselves. The following consultation narrative between a 55 year old unemployed gentleman who has chronic arthritis, and Dr Mark Hutton provides an example of the way that information regarding the benefit of treatment was communicated to the patient. This consultation is representative of the way that the offer of chemotherapy was frequently presented to patients.

In 29 out of 55 consultations, chemotherapy treatment was offered to patients in a similar way as that illustrated below. Typically, the oncologist summarises the advantages and disadvantages of chemotherapy treatment, followed by a statement that the extent to which the therapy will be effective was uncertain. In 29 out of 55 consultations the patients accepted the doctor's recommendation. The following patient attended with his sister.

Sister. Does he still have cancer?

Dr Hutton. He's had a cancer that's been removed, and as far as we can tell it's gone. What they did find is that you have cancer in your nodes. It doesn't mean that it's spread elsewhere, but not necessarily. They looked in the liver and they can't see it, but there is a risk it can come back in the future. The chances are it won't come back, but it might, that's why you're here. If it hadn't spread to the nodes treatment could be beneficial.

Sister. So he doesn't have cancer?

Dr Hutton. No.

Sister. That's all I wanted to know.

Dr Hutton. We don't know what's the best treatment, that's why we're involved in a trial. We don't know what's the best combination. We don't know whether having a combination of drugs is better than just the two-5-FU and folinic acid. Would you want to take part?

James. What are the side effects?

Dr Hutton. You get an injection. Some people get it bad and some don't, so we'll have to adjust the dose. Chemo can affect the blood so you'll be more susceptible to infection. You might be admitted, but that's rare. So you should get in touch quickly. Some people get an active tablet and some don't get an active tablet. It will give you a metallic taste in the mouth.

James. Your hair doesn't drop out these days?

Dr Hutton. No. You should read these details of the study and if you're happy with it we would ask you to sign (Observation 13, p2).

(Duke's C rectal cancer, widowed, unemployed, 55)

During this consultation, (which lasted 19 minutes) the oncologist was recommending that the patient should have chemotherapy although there was some uncertainty if the treatment would prevent future recurrence. The patient and his sister accepted the offer of treatment, assuming that it would help to prevent recurrence, even though there was a question mark against the extent to which treatment would be beneficial. Thus, this consultation is an example of the way that some patients accept the offer of treatment in cases where the likely benefit is uncertain. What seems to be the deciding factor is the clinician's recommendation. The following interview passage with the same patient indicates that he felt that the chemotherapy would help to prolong his life, even though the above consultation narrative suggests that the doctor was uncertain about the likely benefit of the treatment.

Interviewer. Would you say that the possibility of cure is an important factor why you chose to go for this chemotherapy treatment?

James. It's very important. If there is anything then I hope it's going to cure it...Then they said its (the chemotherapy) improved a hell of a lot in ten years. I've got more confidence that its not gonna come back if I take it. They said, as far as they were concerned it was gone (the cancer), they've taken it all away. That was good enough for me. But as I said, I wasn't thinking of taking up treatment until they sort of told me I've got a better chance of getting rid of it. When you get it explained like that then it's only one choice, you got to go for it.

Interviewer: If you were to summarise the main reasons why you chose the treatment what would they be?

James: Without it, it could come back. With it I got a chance that it might never come back. That's the main reason. You only got two choices. Do or die (Interview 34, p5).

(Duke's C rectal cancer, widowed, unemployed, 55)

The most important factor in the patient's decision to accept treatment was the oncologist's advice that treatment was the best way of eradicating the cancer. Although this patient had an advanced stage cancer it is interesting that he still felt quite optimistic that chemotherapy might "cure" him or prevent the cancer from coming back. It appears, therefore, that even though the oncologist indicated that the benefit of treatment was uncertain, the patient was persuaded to

accept the chemotherapy as a way of maximising his chances of 'cure'. The following consultation between Dr Fenton and Eileen, who is a 61 year old patient, demonstrates how the oncologist explained the benefits of treatment to the patient emphasising the fact that treatment may not be effective. The patient attends with her daughter who is in her 30s.

Dr Fenton. Did the surgeon say what we ought to do?

Eileen. They told me that we'll keep it at bay here.

Dr Fenton. The question is do we need preventative treatment. We've found that treatment will be beneficial for people like you. They took the surrounding wall, the cancer extended to the surrounding wall. Even though the surgeon took it all away there is a fear that there may be cancer in the wall and in the blood vessels, even though we cannot see it.

Daughter. She listened to so much gossip that she's frightened.

Dr Fenton. The surgeon may have cured you, but we can't be sure. We may not have got rid of them for sure. We know people are cured with chemotherapy.

Eileen. Will my heart be affected?

Dr Fenton. No. Some people are laid low. Usually during injections you feel ok. The main side effects are a week after injections. You could get a sore mouth. The other side effect is diarrhoea. It's unusual for side effects to be too bad. Two to three percent of patients have to come into hospital. Other side effects involve rashes and sore eyes. Hair loss affects less than five percent of patients. The absolute benefit is as good as for breast cancer. In breast cancer the chemotherapy is new, we'd like you to take part in a trial. Would you be happy to take part in the study?

Eileen. Of course I would. This doesn't sound as bad as I thought it was.

Dr Fenton. Like I said some people are laid low and most are ok. (The patient then signs the informed consent form on the spot without reading it).

Eileen. I've had a lot of cancer in me then?

Dr Fenton. The good thing is it wasn't anywhere else. But there are warning signs. Have I been clear about the treatment and why you need to have it?

Eileen. Yes (Observation 46, p1).

(Duke's C colon cancer, retired school caterer, widowed, 61)

The oncologist explains the uncertainty surrounding her condition and the effectiveness of chemotherapy treatment, and finally encourages her to accept the chemotherapy. For instance, he states that "the surgeon may have cured you but we can't be sure", and then goes on to say "have I been clear about the treatment and why you need to have it?" Eileen does not play an active part in the decision-making process, since the offer of chemotherapy was enough to convince her to accept.

During the interview (below) Eileen claimed that she accepted the chemotherapy since it gave her more confidence that she would overcome her illness. The treatment made her feel secure in the sense that something was being done to 'fight' her cancer. Her decision to agree to the treatment was also determined by the need to protect herself from future anxiety stemming from the possibility of recurrence. Thus, Eileen interpreted the risks and benefits of chemotherapy treatment in a more positive light, even though there seemed to be quite a lot of uncertainty regarding the effectiveness of the treatment to which she consented.

Eileen: I think I would always choose chemotherapy because I think that when you're having a drug you feel as though you're being taken care of and nothing's gonna happen to you. And I think, like you say, whilst patients go off the chemotherapy, then if they get the slightest little pain they think that's it again whereas while you're on the chemotherapy you just feel secure.

Interviewer: Are there any other factors which have influenced why you chose to have chemotherapy?

Eileen: Gives me confidence that they're helping me and I feel safe, nothing else really. It makes me carry on and not think about the actual cancer because I feel the needle is giving me faith. It's weird (Interview 24, p15).

(Duke's C colon cancer, retired school caterer, widowed, 61)

The following consultation, which lasted 20 minutes, was conducted between a 73 year old patient and Dr Fenton. The patient came with his wife. This consultation illustrates how the oncologist explains the uncertain benefit of treatment, and leaves the final decision to the patient. It is interesting how the clinician does not provide a recommendation to the patient but leaves the decision entirely to the patient.

Wife. Can you tell us a bit more because we're in the dark.

Terry. We're in the dark.

Dr Fenton. You had a small malignancy in the colon. (Note the use of the word "had"). It was two and a half centimetres in diameter. The reason why you're here is, beside there was a tiny lymph node. The question is whether to give you any chemotherapy.

Wife. I had visions of it being rampant.

Dr Fenton. The question of whether preventative treatment is revisited. Chemotherapy is advantageous, and common practice for people in their sixties. Compared to other types of treatment of this sort, the side effects are not so bad. The side effects involve sore mouth, diarrhoea. We're not entirely sure whether benefit is clear in your case. We're involved in a study. I don't decide whether you have the treatment, a computer does. How do you feel about it?

Terry. My wife's got to bear the brunt of it.

Dr Fenton. You could well have been cured as a result of the operation. I can't say for sure. The involved lymph node is a warning sign.

Wife. We have to be guided by you.

Dr Fenton. That's why we're doing this study, because we're not entirely sure of the benefit of the chemotherapy. There's a fifty-fifty chance of having the treatment. Do you want time to decide?

Terry. I'll leave it to the computer. I don't like things hanging over my head (Observation 28, p1-2).

(Duke's B/C colon cancer, married, retired aircraft engineer, 73)

Terry was finally randomised into the 'no treatment' arm of the trial, however, he interpreted the decision in terms of a positive outcome for himself.

Interviewer. How do you feel about the fact that he (oncologist) explained the trial to you and prepared you for the treatment and then you weren't selected?

Terry. He turned around and said that he didn't think that I needed it.

Interviewer. Did that give you confidence?

Terry. Well I was quite happy, that was just an added bonus.

Interviewer. Would you have preferred to have chemotherapy?

Terry. If I needed it, but I don't know if I need it. I understand that there is a blood test to see if you got cancer, but if this is true I don't know.

Interviewer. And if you do need chemotherapy were you told that they will give it to you?

Terry. Oh yes, he said there will be no reservation if it was found necessary that you need chemo they'll give it to you.

Interviewer. When he said that he didn't think that you needed chemo anyway, did that make you feel much more confident in the final decision that was made?

Terry. I just felt satisfied with what he was saying. Computer said no, he confirmed, he was quite happy that I didn't need chemo.

Interviewer. Do you feel that you would like to be more involved in deciding on your treatment rather than simply leaving it to the doctor and the computer?

Terry. No I don't think so because I don't know enough about my condition. I've been told they removed three foot of it, but what's the possibility of it being somewhere else in my system? (Interview 33, p6).

(Duke's B/C colon cancer, married, retired aircraft engineer, 73)

This interview passage indicates how Terry was prepared to trust the oncologist's recommendation that treatment was not necessary (after randomisation into the 'no treatment' arm of a trial) especially when the oncologist explicitly claimed that he was unsure if benefit was clear in his particular case. Thus, the clinician's opinion that further treatment was not necessary served to reassure Terry that having no treatment was the 'right' decision for him. Terry found the doctor's advice particularly helpful because he felt that he did not have sufficient knowledge to make the decision regarding treatment by himself. For instance, when Terry was asked if he would have preferred a greater role in decision-making rather than delegating the task to the randomisation process, he replied "No, I don't think so because I don't know enough about my condition".

Several studies have shown that people experience difficulties in interpreting probabilistic information in a way that makes sense to their everyday experiences. When presented with percentages indicating a future risk of cancer, there is a tendency among individuals to translate the information into categorical or ordinal forms (Gregory and Cotler, 1994; Parsons and Atkinson, 1992). Gregory and Cotler (1994) carried out a study investigating women's

perceptions of genetic testing for Duchenne Muscular Dystrophy, which is a genetically transmitted disorder. They found that respondents translated percentages into ordinal terms such as 'high' or 'low' risk, so that the probabilistic was expressed as a matter of certainty. Charles et al (1998) found that breast cancer patients interpreted probabilistic information in ways that made sense to their everyday lives and enabled them to cope with the knowledge that they would either live or die. The current study indicates that individuals do not simply interpret risk information in categorical terms, but they often summarise the information in terms of a positive outcome for themselves. Even if what they are told by the oncologist is not positive or entirely 'good' news. There is a sense that many informants in this study wanted to maintain a high degree of hope that treatment would benefit them. Being told that the treatment could offer a 10% better chance of survival was not terribly meaningful to them. However, the hope that treatment would provide some remission or maybe even a cure, compelled them to keep a positive attitude. In many cases the possibility of treatment increased their sense of optimism that they could 'beat' their disease. Informants often seemed unable to interpret the risks and benefits of treatment without the oncologist's guidance. Thus, the clinician's summary and interpretation of the pros and cons of treatment was often central to the way informants perceived the treatment.

As demonstrated above, most interview participants kept a positive attitude towards their treatment assuming that it would provide them with some hope of long-term remission or even cure. In the following interview excerpts there was no debate about whether to accept the offer of chemotherapy treatment. The informants felt like they had no choice but to accept, in the hope that the treatment would improve their survival chances. Also, the informants felt they had no choice but to feel optimistic that the chemotherapy would help them in their battle against cancer. The following informant is a 53 year old married gentleman, who works as an electrical engineer. He has a Duke's C colorectal cancer, and was offered chemotherapy treatment by the oncologist.

The following interview passages were selected because they were typical of the range of responses given by informants regarding the risks and benefits of treatment.

Interviewer. When you said you talked to your wife, can you tell me what you discussed, whether it was the right thing to do?

Peter. There was no debate. I didn't question the experts. If it's an expert just ploughing his own little field and he's gonna leave me in trouble I'll be very sad about that. I believe he's got my best interest at heart and I'll be guided by what he says.

Interviewer. When you met Dr Hutton, did you feel that you had an option to say I don't want treatment or did you feel that you didn't?

Peter. We'd already decided that I was gonna have treatment. Seeing

Dr Hutton, there wasn't any question in my mind whether we should or whether we were not gonna have the treatment. There it was, it was there. We were there to meet him to tell me what the treatment would be.

Interviewer. The surgeon prepared you for that?

Peter. He prepared us for that.

Interviewer. It's also for peace of mind you went for it?

Peter. It's the best we can do isn't it. The best advice is to do this and keep our fingers crossed. My trust is absolute in him, so I'm gonna go for this, and no matter how bad I feel (Interview 37, p23).

(Duke's C *recto-sigmoid cancer, married, electrical engineer, 53)

Peter felt highly certain that he wanted to have the chemotherapy treatment, even if the treatment was to result in adverse side effects. Indeed, he expected the oncologist to offer the option of chemotherapy, which he did not attempt to question. The following interview narrative with a 66 year old married woman with advanced stage colorectal cancer, indicates a similar desire by the patient to maximise her chances of survival by accepting treatment. Thus, the hope of longer survival seemed to spur this woman to accept the chemotherapy option.

Interviewer. We were talking about the benefits of chemo and things like that. What was it that Dr Fenton explained to you about it?

Brenda. I don't really think there was very much said about the benefits of chemotherapy as I say to you, if it's something better than nothing then you have to take advantage of it as far as I'm concerned.

Husband. You're grasping at straws aren't you?

Brenda. Of course you are, of course you are (Interview 8, p14).

(Duke's D colon cancer, married, retired domiciliary worker, 66)

This informant stated that she wanted to prolong her life for as long as possible and chemotherapy offered the only hope. In addition, although there was some discussion about the risks and benefits of chemotherapy treatment, Brenda chose to accept the treatment on the basis that "something is better than nothing". As with Peter, Brenda felt that even the smallest chance of

* This is the junction between the rectum and the colon.

cure or remission would justify pursuing the treatment option. The following informant (a 55 year old single woman, who works as a property developer) also felt that a discussion of the advantages and disadvantages of chemotherapy with the oncologist was almost peripheral to her decision to accept the treatment option.

Linda. He (the consultant) and the younger surgeon came and saw me and he said, have I thought of chemotherapy, and I said-I never even given it a thought in my life. Well he said, I don't know, he said, it's worth thinking about, he said, I think I'll speak to one of the consultants and within you know sort of an hour Dr Fenton was there, the cards were on the table uhm. Did I want it, did I not want it? Then I didn't sort of give it any other thought, there's no other choice, I mean I had to accept it, there was nothing else I could do. So obviously I went ahead with you know, doing it as soon as they could, and it was all arranged (Interview 19, p21).

(Duke's C colon cancer, single, property developer, 55)

Linda felt that if there was some chance of recovery from her illness then she would accept the chemotherapy option. There did not seem to be a realistic choice for her not to accept the treatment. The fear that the cancer could advance was a good reason to have the treatment. There was no discussion of the risks and benefits of treatment as far as Linda was concerned, because the offer of chemotherapy was a necessity not a choice. Similarly, the following 64 year old retired steelworker with a Duke's D rectal cancer, also accepted the offer of treatment in the hope that it would improve his chances of survival.

Interviewer. So you see the treatment as a line of hope?

Gavin. Yeah, it gives you a little hope doesn't it. Otherwise I wouldn't have bothered. If he said you can try this but it ain't gonna do you no good, I should have said well what's the point in trying it, no point in trying it is there if it won't do you any good.

Interviewer. How do you feel about being entered into an experiment?

Gavin. I'd sooner not have it obviously but if it's the only chance you've got you haven't got much choice in the matter have you.

Interviewer. What was the rationale behind your decision?

Gavin. He asked me if I wanted it and he said it's up to you entirely, you can have it or you don't have to have it. He said it's the best that I can offer you. So I thought if it's the best he can offer I got to try it and see (Interview 16, p9).

(Duke's D rectal cancer, single, retired steelworker, 64)

Similarly, Gavin did not perceive that he had a real choice of accepting treatment. He felt that the chemotherapy offered him a degree of hope, and on that basis he accepted the treatment. Gavin did not embark on an evaluation of the pros and cons of treatment with the oncologist. He simply accepted the offer on the basis that "if it's the best he can offer I got to try it and see".

Not all patients who participated in the current study accepted the oncologist's recommendation to have treatment. Out of a total of 55 consultations 8 patients expressed reservations about undergoing treatment, and 4 rejected the offer of treatment outright or following a period of reflection. Some did play a more active role in interpreting the risks and benefits of treatment, and sometimes their evaluations conflicted with those of the clinician. The following interview passage indicates that although the oncologist thought that further treatment was beneficial, the informant felt that it was not worth undertaking. This interview was conducted with a 70 year old man who has a colostomy. He lost his wife to cancer several years ago, lives alone, and has revealed during the interview that he has been depressed since the death of his wife.

The following three interview excerpts represent typical responses provided by informants in this study, concerning this theme.

Interviewer. You were very determined to be told the truth. Why?

Arthur. Well, three years ago I lost my wife, she had lung cancer. Without her life isn't the same at all. I just as soon be dead. I told my doctor that. I haven't got the courage to do that. Some people think that if you commit suicide you're a coward, I don't, I think they're entitled to do what they want to do, I just wish I had the courage sometimes. One or the other, I couldn't stand the pain, they (surgeons) got rid of the pain (Interview 27, p23).

(Duke's C rectal cancer, widowed, retired aerospace manager, 70)

His desire not to undertake further treatment was, to some extent, shaped by his perception that life has not been worth living since his wife's death.

Arthur: I then said what sort of chances, what are the odds. She said a man of your age with your category of cancer, the chances of living another five years was three in ten. And I said, after the chemotherapy what chances have I got. I was gonna have five days of chemotherapy and at the end of it I'd be wacked, and then I'd have three weeks rest before they give me another five days blast of it. I thought well that's not giving any rest. Lets get on with what's left of life. My impression was that the doctor was being logical and sensible. To increase your

chances by one tenth you go through all that? For what purpose? At my age, I'm seventy one. I've got to go through more pain but perhaps get one tenth more. I didn't see that at all. And everybody had told me I looked well, so what the devil, perhaps I'll beat this thing anyway. Cos I suppose your body fights against these things. I might die of something else.

Interviewer: Did she say that you may already be cured anyway?

Arthur: No she didn't. She said it was difficult to exactly determine what's happening. She said we don't know whether the treatment will be effective. That's what it meant to me. So I thought there's another reason. She said all that before she told me the percentages. The percentages finally convinced me that it's not worth the hassle...The ruddy stats that have been gathered, and you know, there are fluctuations in stats. There are a hundred percent mark some of them, some of them are zero as well. They need to advise the best course to take (Interview 27, p5).

(Duke's C rectal cancer, widowed, retired aerospace manager, 70)

Arthur was told by the oncologist that chemotherapy would probably improve his chances of survival. However, he felt that the benefit was not high enough to justify having to endure six months of rigorous treatment. The informant also felt that he was too old for such treatment and he preferred to return to living a normal life. This example strongly supports the case that much of decision-making in oncology involves a value judgement that cannot always be made by the clinician. A patient's preferences are often shaped by personal and social circumstances, and not only by factors relating to clinical effectiveness. Arthur decided that the benefit that treatment offered was too small to justify having to endure six months of chemotherapy treatment. However, what reassured him that he was making the 'right' decision was the oncologist's confirmation that there was no guarantee that the treatment would do any good in his case. The patient played an important role in interpreting the risks and benefits of treatment by indicating that he felt he was too old to undergo a prolonged course of chemotherapy, which might not be effective in eradicating his cancer.

The following patient also rejected the offer of chemotherapy on grounds of age and because he felt that he did not need the treatment.

Robin. At my age, I'm 75, I didn't want to be tied down, as it were. That was the only reason, a selfish reason really (for refusing chemotherapy).

Interviewer. When you went to see Dr Fenton, when you were discussing the treatment options, did he try to persuade you or dissuade

you regarding the treatment?

Robin. He was extremely pleasant and extremely neutral, he didn't push it at all.

Interviewer. Did he make you feel as though the decision was yours?

Robin. Oh yes, and as soon as the radiotherapy treatment was complete the chemotherapy was never mentioned again.

Interviewer. Did he make you feel that you made the right decision?

Robin. I don't think it was ever suggested that I needed it. It was just taking part in an experiment to find out what the results might be.

Interviewer. You didn't think that the treatment would be of benefit to you?

Robin. No.

Interviewer. Did the experiment put you off?

Robin. Yes it did.

Interviewer. You didn't think it would benefit you but only future patients?

Robin. That's right. It was a purely selfish decision (Interview 13, p24).

(Duke's C rectal cancer, married, retired office worker, 75)

Robin decided not to have the chemotherapy simply because he did not feel that it would benefit him, especially since the treatment was administered as part of an "experiment". In addition, he felt that the treatment would "tie" him down, which he felt was a distinct disadvantage given that he was 75 years of age.

The following passage from a consultation between a 67 year old man and Dr Smith (Senior Registrar) also demonstrates how this patient decided to reject the doctor's recommendation by refusing the treatment option. The consultation lasted 20 minutes.

Dr Smith. What have they (surgeons) said to you about further treatment?

Alan. They're leaving that to you. It's not for me to say. They sent me up

here for...

Dr Smith. There's two things we need to discuss. They've taken it all out. Sometimes it's a bit difficult to get a good margin of good tissue when you can't see. We like to get a decent amount of normal tissue because the cancer can creep along. They got the tumour out completely. We will give you radiotherapy treatment to stop the seeds coming back. Radiotherapy will involve coming every day. We give it in lots of tiny doses.

Alan. That would entail coming in every day.

Dr Smith. Every day. To try and stop it coming back in the local area. Can you lie on your tummy?

Alan. It might be a bit awkward (due to the stoma).

Dr Smith. We do a planning session. We always treat exactly the same place. Treatment would start a few weeks later. And it would be five and a half weeks. The treatment will make you a bit tired, diarrhoea. The water works may get a bit irritated because the bladder's next to the rectum.

Alan. I leave it up to you.

Dr Smith. The other question is uncertain. You may have heard about chemotherapy. When we looked at the tumour we look at lymph glands. You heard of them?

Alan. Yes but I don't know what they do.

Dr Smith. They're part of the immune system. Tumour cells can go to lymph glands. There's therefore a chance that they may have spread. In your case there were none in the lymph glands. Half the patients will be randomised to have and half not to have chemotherapy. We do this to see how both groups do. There are benefits to chemotherapy but there are side effects. It can make you feel tired, you can have diarrhoea and mouth ulcers and you could be susceptible to infection. We don't know if chemotherapy will improve your survival.

Alan. I'm 67. I would like to go off on a high.

Dr Smith. Some people want to have everything, some think that the op's enough. The other is whether you think one way or the other or whether you want chemo.

Alan. I don't know. I'll have to talk to the wife. What do you think?

Dr Smith. I don't know. There's a chance that the chemo would help but

I don't know your chances. We're not certain. You have to tell us that if you agree then that you are happy with that. If you decide not to have the treatment then that you're happy with that decision. If you decide not to take part I would say that's perfectly reasonable.

Alan. At the moment I would say no (Observation 49, p2-3).

(Duke's B rectal cancer, married, retired Police Officer, 67)

In this consultation the oncologist offered radiotherapy and chemotherapy treatment to the patient, but she also stated that the benefits of chemotherapy are uncertain. Consequently, Alan could not make a decision and wanted to discuss this further with his wife. Indeed, he felt that he wanted to "go off on a high" and six months of chemotherapy might adversely affect his quality of life. Coupled with the fact that the doctor did not offer a clear recommendation, he finally stated that he did not want the chemotherapy. Thus, Alan felt that the likelihood of experiencing adverse side effects, and the lack of certainty that treatment would be of benefit, influenced his decision to refuse treatment. Thus, in this consultation the patient played a key role in interpreting the risks and benefits of treatment.

Modes of adaptation to uncertainty

The results so far have shown that many informants tended to cope with uncertain information by interpreting it in terms of a positive outcome for themselves, a process that also helped them to rationalise the treatment decision. However, on approaching the final stages of treatment, most interview informants expressed a desire to know whether their treatment had been 'successful', and if their disease had progressed any further. During the initial stages of therapy, informants did not actively search for information relating to the effectiveness of treatment, however, this changed over the course of time. Even those informants who had no oncological treatment tended to express a greater concern about the possible outcome of their illness at the follow-up interview than they did previously. This uncertainty was no longer interpreted in a highly positive and certain manner, as in the initial stages of treatment. Rather, there seemed to be a greater level of adaptation by informants to the unpredictable nature of their condition. In short, many informants started to accept the uncertainty surrounding their illness. Thus, the greatest worry for the colorectal cancer patient during the latter stages of treatment seemed to be a concern for the future outcome of the disease.

During the follow-up interviews most informants were less positive than they were previously, but they were more philosophical about the likely outcome of their illness. They wanted to know how effective the treatment had been and what the future course of the disease would be. However, they largely accepted by this stage, the uncertainty acquainted with their cancer diagnosis. The following informant illustrates this changing perception.

The following interview extracts illustrating the views of two informants encapsulate the most typical responses given in this study regarding this theme. Out of 37 initial interviews, 23 informants expressed optimism about their illness and treatment. The remainder simply felt hopeful. However, out of the 28 follow-up interviews that were conducted 24 informants demonstrated some level of adaptation by appearing more accepting of the uncertain outcome of their illness. This suggests that they may have adapted to their illness by accepting the uncertainty, which surrounds its progression. The remaining 4 informants were still very optimistic despite the existing uncertainty about their illness.

First Interview

Interviewer: Before you came to the Oncology Centre what was your impression about your state of health at that point in time?

Patrick: No, I wouldn't say that I was free of the disease. I had a big part of the cancer taken from my body from what they told me at Frenchay, and there were little pieces which they can't do anything about are still there which I was hoping this treatment which I'm having will either disperse it or stop it from going to other parts of my body (Interview 31, p4).

(Duke's D colon cancer, married, retired office worker, 74)

However, towards the end of treatment the informant began to question the effectiveness of his treatment.

Follow-up Interview

Patrick: And then he sees me and he discusses the symptoms. He smiles and he's very pleasant and says everything's alright. It's so easy to accept the word 'alright'. The last time I saw him I said to him well what does it mean 'alright'? He said well, when we had the first scan there was a slight scar where you had your operation and he said it's still the same, it's still there. What it means I don't know. Whether it means that I'm alright, as he says you're alright, everything's going alright and we're very pleased with you. But what that means is a bit hard to know. In fairness to him they're all being very very kind and considerate to me. I think after my six treatments I will say "well what

does this really mean"? Is it getting better or is it getting worse or is it standing still? (Interview 31b, p2).

(Duke's D colon cancer, married, retired office worker, 74)

During the first interview the informant felt optimistic that the chemotherapy would prevent further spread of the disease. However, at the second interview, the informant felt confused about the success of the treatment as the oncologist was unclear about the degree of improvement in his condition. The finding suggests that this informant was optimistic at the start of treatment, whereas towards the end of treatment he had adapted to the uncertainty surrounding the outcome of chemotherapy. This uncertainty was confounded by the fact that, in most cases, success or failure cannot easily be established by means of a medical examination or test. Other informants, on approaching the end of treatment, experienced greater difficulty in coping with the uncertainty surrounding the success of their treatment.

First Interview

Yvonne: So I said to the doctor I got to have it because I got young children, there was no question, so from that point of view that was easy to decide given the fact that he said if you don't have it you gonna go down hill quite quickly (Interview 7, p14).

(Duke's D colon cancer, married, social worker, 37)

Towards the end of her chemotherapy treatment she expressed the following.

Follow-up Interview

Yvonne: Yeah you want to uhm but like they say, oh well, wait till you have your first scan. And then you've got to wait three months to find out a bit of daylight, the drugs to work in the body. And up to that point, I mean, it's like you can't do anything until you know one way or the other. At the moment I feel I need to know one way or the other. I know I've got cancer but I don't know is it working-it's like if I take a tablet, if I got a headache I can take a tablet and I can feel all my headache's going. With this, I got all the rashes and all that to having all the symptoms, but I don't know inside if it's working. So, until I've got the three months cleared one way or the other or when you still got that, you still got it or you haven't got it, it feels like you can't do anything either way (Interview 7b, p5).

(Duke's D colon cancer, married, social worker, 37)

At the first interview the informant clearly believed that chemotherapy would be of benefit to her, since without it her health would deteriorate, with repercussions for her family. Thus, to an

extent, she rejected the possibility that treatment would not be successful, which made her decision to accept treatment a relatively easy task. However, towards the end of her treatment, the informant felt as if she was in a state of limbo caused by the uncertainty that emerged from not knowing if the chemotherapy had been effective. She claimed that she could not make any plans relating to her personal life, and generally felt very unsettled. In fact both informants seemed to experience a high level of anxiety. However, what was specific to both informants was that during the course of the first interview their tendency to maintain a positive attitude towards their treatment may have been a way of delaying or displacing their uncertainty to a later date.

Interviewer. Is there any other reason why you decided to have treatment?

Rebecca. I suppose I thought if I had the treatment I'm gonna be like I was previous before I had the operation. You don't know how to plan your life when you get....when you go in for operations. I mean, two holidays I had to cancel.

TS. You were quite happy to go along with the treatment?

Rebecca. Yes.

Interviewer. What did the treatment mean for you personally?

Rebecca. Well to me it meant that if I had it I would be cured. That is what I was thinking. I thought it was going to kill off anything that might be there, I was gonna be cured, it was gonna prolong my life (Interview 4, p11).

(Duke's B rectal cancer, widowed, retired School Caterer, 70)

Rebecca felt that the treatment would enable her to return to a normal life, and her son and daughter encouraged her to accept the treatment. Her son also had radiotherapy in the past and seems to have recovered completely, which was another reason why she was eager to accept the treatment. Thus, Rebecca felt confident that accepting the offer of radiotherapy treatment was the right thing to do. Five months after receiving her treatment Rebecca expressed a degree of uncertainty about the possible outcome of her illness.

Interviewer. What is your state of health now?

Rebecca. I'm fine, very well.

Interviewer. Would you describe yourself as being cured?

Rebecca. I think I am. Dr.Fenton said, they can't say I'm cured, you can never say a hundred percent. He thinks I'm doing fine, he thinks it's ok. Nobody's got a crystal ball and can tell can they. You just got to go on with your life now (Interview 4b, p11).

(Duke's B rectal cancer, widowed, retired School Caterer, 70)

During the follow-up interview, Rebecca remained confident that the treatment would help in her recovery. However, she seemed to realise that there is no way of predicting if the cancer will return or if the treatment had been successful. But she also felt that she needed to resume her life and take things as they come.

The tendency for individuals to interpret information in a more positive and certain way reflected their need to break down complex information into manageable quantities. The uncertainty, seemed to remain latent, and could not be dispelled permanently by the patient. Indeed, the issue of uncertainty seemed to resurface when the issue of treatment effectiveness was revisited. Most oncologists in this study limited the content of the first consultation with their patients to a discussion of the likely costs and benefits of treatment, and they seldom discussed future management plans. These findings indicate that patients could benefit from an initial discussion of the longer-term problems that they may encounter which in turn could help to limit future anxiety or worry. Indeed, such information could also influence the treatment decisions that patients make.

Participation in decision-making

Perceptions of choice in decision-making

Most patients who were observed in the clinics seemed to be largely concerned with the need to decide whether or not they wanted to undertake any treatment. However, central to that concern, was whether chemotherapy would provide a cure. In oncology, the language of 'cure' is replaced by the language of risk, probability, and prevention which can complicate the patient's decision-making task. The fact that the intentions of treatment in oncology change from 'cure' (as in surgery) to 'prevention' potentially gives patients a greater scope for involvement in decision-making. If the intention of treatment is to prevent the spread of cancer, rather than cure it, then the question of whether to accept treatment becomes increasingly value-laden. Consequently, there is

more opportunity, and need, for patients to consider their values and preferences within the decision-making process.

A certain degree of confusion exists in much of the relevant literature of what constitutes 'decision-making'. Some studies conducted on the decision-making practices of breast cancer patients (Meyer et al, 1995; Beaver et al, 1996) have not adequately defined the activities which take place within the consultation. As illustrated earlier, decision-making may often be the end point of a lengthy process of evaluation, negotiation, mediation, 'problem-solving', and personal reflection. Thus, the strategies that lead to a decision cannot be sufficiently understood if 'decision-making' practices are defined too narrowly and include only the end-points of what is often a complex process. Although it is important to understand why doctors and patients make certain decisions, it is just as important to understand the avenues that lead them towards those decisions. A conceptual distinction between 'problem-solving' from 'decision-making' could be useful here, whereby the latter task encompasses a much wider range of activities than the former.

Many studies, predominantly concerned with decision-making in breast cancer have concluded that patients prefer the doctor to make treatment based decisions (Long, 1993; Deber, 1994; Meyer et al, 1995; Beaver et al, 1996). However, the conclusions reached by these studies tend to overlook the various 'strategies' that are often inherent in the 'decision-making' task. For instance, even though most informants in the current study felt that they made the final decision about their treatment, the clinic observations suggest that decision-making was guided by the oncologist. However, this does not mean to say that patients played a limited part in the process of making their decisions. On the contrary, many patients 'negotiated' the decision with their oncologist, by endeavouring to resolve the uncertainty surrounding the decision-making process. This theme will be revisited in the second part of this chapter.

Decisions in oncology involve a value judgement that often means having to balance the potential benefits against the rigours of treatment. This is because treatment benefit for many people is 'relative' rather than 'absolute'. In at least one respect the interview data seems to contradict this assumption. That is, most interview informants preferred to undertake treatment even when benefit was limited and when the side effects were often adverse. Even though informants felt that they had an option to accept or refuse treatment, they did not feel that this choice was a 'realistic' one. For example, 30 out of 37 informants felt that they *had* to accept the treatment option when it was offered to them.

The interview narratives provided in this section were selected because they were representative of all the responses provided regarding the issue of treatment choice.

Interviewer: Then you discussed the treatment options. What did you discuss?

David: Do I want to go on with the treatment. Do you want treatment or not have treatment. It's like saying do you want to die very quickly or do you want to die a slow long lingering death. So I went on the chemotherapy option. It wasn't a very good option really (Interview 35, p3).

(Duke's D colorectal cancer, married, local government officer, 64)

This informant clearly felt that the option of having chemotherapy was not a 'legitimate' one since the choice of having treatment presented him with two undesirable alternatives. He felt that the treatment gave him the option to decide on the process of dying, rather than on a realistic chance of survival. The following informant, however, felt compelled to accept chemotherapy treatment in order to prevent any future worry and anxiety.

Interviewer: What was the rationale behind your decision to have treatment?

Wife: You feel that something's being done.

Patrick: We talked it through and I felt that I was going to have something done. On the other side if I said I don't want any treatment you could keep living through your life, and think to yourself, well, when am I going, when is it going to take over. Where I feel that if I'm having treatment, something is being done, and it might arrest it or stop it spreading (Interview 31, p6).

(Duke's D colon cancer, married, retired office worker, 74)

This informant felt that he had to accept treatment in order to minimise the fear of recurrence and any emotional stress that might be generated as a result. The prospect of having no treatment would aggravate his fear and uncertainty that the cancer could return. Thus, the need to accept the treatment option was a means of eliminating any potential sources of worry and anxiety. Other informants commonly felt that accepting the treatment option would help to reduce the sense of guilt or self-blame if the illness was to advance and the opportunity of therapy was not taken.

Angela: The only thing which I'm thinking is, if I don't go ahead and have it done and it's gone further, I shall blame myself for not going through with it. And if I go through with it now and it's gone further then it's OK, I've done my best and it's not my fault (Interview 25, p5).

(Duke's C colon cancer, widowed, retired, 74 – Italian)

For this informant, accepting the treatment was a way of absolving herself from the responsibility for the future course of her illness. Accepting the treatment enabled the informant to manage the potential negative psychological and emotional costs which could otherwise result. Thus, the treatment for her was less a choice and more a necessity. Other informants, however, wanted to accept treatment, partly because it would give them access to an important information source. This was crucial in helping them to understand and manage their illness. The following narrative is one example.

Graham: But the other thing, I feel now I have a season ticket to, if I don't feel too right, finding out what the bloody hell was wrong, you know, I'm on the books, I'm a regular. It's like having a seat at the Royal Opera House. I took it because it was there and because in my view it would be too risky not to take it up (Interview 17, p14).

(Duke's B/C colon cancer, married, retired fire brigade chief, 63)

For this informant the option of having treatment would be too risky to reject, since he saw it as an opportunity for learning more about his illness. In addition, it gave him access to information that could help him manage his illness in the long term. By accepting the treatment he felt like something was being done about his condition.

One informant also felt that combining the chemotherapy with other complementary therapies, such as visualisation techniques, would help in her endeavour to adjust more successfully to her illness. Thus, the chemotherapy would help her to adjust psychologically to the cancer.

Ann: What I think is that everything on the earth is designed to make me feel positive and to accept the medical input in the most constructive way, so from that point of view I think they (alternative and orthodox medicine) are totally complementary. And I will see myself getting my visualisation before chemotherapy starts. I ought to consider John's (husband's) first remarks, 'good, that gives you a chance to get the visualisation aspects', so when I go in, my chemotherapy is accepted into me in the most positive way possible. So I don't think I can do one or the other, I see all this stuff getting me into the best possible frame of mind. Either to live longer or to die better and to accept the toxicity. To accept that in the most positive and constructive way so I can come out really much more integrated (Interview 18, p11).

(Duke's C recto-sigmoid cancer, married, complementary therapist, 66)

The informant perceived both the visualisation techniques and the chemotherapy as complementary. For her, they were both working not just to maximise her chances of survival, but also to put her in a better frame of mind. Again, the option of no treatment was not an

acceptable one for this informant who was convinced that the chemotherapy would assist in her physical and psychological 'fight' with cancer. Informants who accepted treatment did not simply feel that having therapy would reduce their uncertainty, they felt that it was a necessary option which would enable them to adapt psychologically to their illness. Accepting the offer of additional treatment usually reflected a need to adjust to new circumstances and come to terms with their condition. Thus, in many cases informants perceived the chance of undertaking six months' of rigorous treatment in a positive light, since it represented an opportunity to come to terms with their condition, whilst offering some hope.

Some informants (4 out of 37) felt that they had no choice but to reject the offer of treatment because their cancer was too far advanced to be of any benefit. The following informant was a 74 year old man with advanced colon cancer.

Colin. He put it in such a way that you couldn't disagree really, because you're talking to a medical man that knows the score. He said, if you had an operation it was a very very serious operation, and my age I suppose. He said it was in more than one place didn't he. I suppose it spreads very quickly. Once it starts it spreads from one place to the other. We were not annoyed and I haven't been upset about the decision because you got to think straight in these circumstances haven't you. And what is best, what the top doctor suggests, I think you got to go with. The way it was put to me you couldn't disagree really. Cos you can't argue with a professional medical man can you.

Wife. I suppose if you said you had said you wanted to try some treatment you would've had it, but what is there in making you worse than you are? We just had to accept it really.

Colin. I thought that the treatment would spoil the few months I had and make them more unpleasant. I might as well enjoy what I've got because I think I got the impression the ultimate end will be the same, but you could go through a lot of discomfort reaching that far (Interview 14, p15).

(Duke's D colon cancer, married, retired 'Fitter', 74)

Colin had advanced colon cancer and did not feel that having a prolonged session of chemotherapy would cure him or extend his life. Thus, he had no choice but to refuse the treatment on the grounds that it would cause additional suffering and inconvenience during the last few months of his life.

The findings indicate that even when the benefits of treatment are limited, most colorectal cancer sufferers may still prefer to undertake treatment for personal reasons. For example, they may feel that treatment will strengthen their ability to cope with their illness and allow them to adjust more effectively to their new circumstances. It is therefore, important for oncologists to

recognise patients' personal and psychological needs for opting for treatment, even when evidence of clinical effectiveness may come into conflict with their preferences. The process of undergoing oncological therapy may satisfy important psychological needs that could help patients adapt to their condition. Thus, the need for patients to reduce the likelihood of future anxiety or self-blame, which could be generated by having no treatment, should be recognised within the context of the decision-making process. However, some informants may believe that they have no choice except to reject treatment as they anticipate that it will be of limited benefit.

'Right' and 'wrong' decisions

Some studies (Charles et al, 1998) have indicated that cancer patients often question whether they have made the 'right' treatment choice. However, Charles et al were unable to conclude whether patients felt they made the 'right' or 'wrong' decisions due to the lack of any long-term data. In the current study the majority of informants (34 out of 37) felt that they had made the 'right' treatment decision when asked at the initial interview. The remaining 3 could not really say whether they had made the right choice, or they felt that the question was inappropriate or too difficult to answer. However, towards the end of their treatment course 20 out of 28 informants felt they were unable to judge if they made the 'right' decision as there was no way of knowing if treatment had been effective. (The other 8 out of 28 informants were more confident that they had made the 'right' decision). During the follow up interview Graham could not decide whether he had made the right decision regarding treatment.

Graham: I was asking about it when I saw him last week, and it will be two or three years before they have any idea whether it was a good thing or a bad thing.....The only hope I have out of this is that they get a positive result, you know, that they'd be able to say oh this is good treatment or no it's a waste of bloody time. I hope they don't come out and say well it appears that in twenty two and a half percent of cases they kill people, in twenty two and a half percent they make them bloody worse and you know (Interview 17b, p6).

(Duke's B/C colon cancer, married, retired Fire Brigade Chief, 63)

Graham claimed that he did not know whether the decision to undertake the chemotherapy was a good or a bad idea as only time would tell. However, for him accepting the treatment involved investing a high level of hope in the effectiveness of the chemotherapy. Thus, his interpretation of the decision to accept treatment was not embedded in a normative language of 'right' and

‘wrong’. Although he believed that accepting the treatment was appropriate, he nevertheless, could not judge whether he made the ‘right’ or the ‘wrong’ choice. Similarly, other informants felt that they could not categorise their decision to have treatment as ‘right’ or ‘wrong’, since all decisions involve advantages and disadvantages.

Ann: I really think that had he not halved it (the dose) what I was going through was to say I'll go for three months and the doctor told us that he doesn't know himself whether six months is enough or too much or whether one month. Whatever, we don't know, it's just an arbitrary figure.....It was a big bolt to my system and I was going to say after the three I'm not doing any more. Simply because I felt I didn't want to and I just felt that it was a bit of a nightmare really.....I think I fairly understood the doctor. I think that if I did stop now and then I got something next year, I would think that I made a mistake. Whereas, if I do keep going the treatment would cure me (Interview 18, p2).

(Duke's C recto-sigmoid cancer, married, complementary therapist, 66)

Ann was experiencing adverse side effects, and she believed that the decision to undertake the chemotherapy did have this distinct disadvantage. Nevertheless, the rigours of treatment were outweighed by the hope that the treatment would provide a cure. Thus, the decision to accept the treatment was not viewed as ‘right’ or ‘wrong’. Rather, it was seen in both a positive and a negative light, and in terms of hope and uncertainty. Harold, on the other hand, felt strongly that the decision to have chemotherapy was the most appropriate choice for him even though the outcome was uncertain. In a similar vein to the comments made by the previous informant, Harold was not sure if the treatment would help. However, he suspected that it would provide some benefit. He could not evaluate the extent to which he made the right decision with a simple ‘right’ or a ‘wrong’ response. Instead, he responded to this question with some reservation, mainly due to the uncertainty surrounding the treatment.

Harold: I think it was probably the right decision. We'll never know will we? Perhaps someone who has not taken treatment than taken the treatment, you can't really tell. The surgeon put it to me at the time, he said there's no guarantee, but he said it is a preventative course and we think it would be wise thing to take. You can't guarantee it will help. It's worth taking the chance I think (Interview 28, p1).

(Duke's C colon cancer, widowed, retired insurance broker, 75)

In contrast, the following informant had no reservations about her initial decision to accept chemotherapy. Indeed, she felt more secure and confident whilst undergoing treatment than she felt after finishing her six month course. She felt that something was actively being done to

counteract her disease. Thus, to this extent she believed that the decision to accept treatment was the best one for her. However, like many other informants, she felt helpless after completing her treatment course as there was nothing more that she could do to counteract her cancer.

Interviewer: Do you think that uncertainty is difficult?

Linda: Yes I do. And it's better when you're having your chemotherapy to now, because you're still having treatment for it. Now it's sitting dormant. There's nothing else I can do for the time being. If he'd given me six months' pills that were still sort of preventing it as well, you'd probably feel a lot happier, but there's nothing else you can do now, you're not being ignored but you're finished with at the moment (Interview 19b, p8).

(Duke's D colon cancer, single, property developer, 55)

Dianne, however, expressed a strong regret that she accepted the chemotherapy because she experienced debilitating side effects from which she had not recovered, and consequently her treatment was stopped.

Dianne: I don't think they explained things fully as to what the risks were kind of thing. I didn't think I was taking any risk whatsoever. Had I known I was taking a risk I would have said no. I wouldn't go on with the treatment.

Husband: They could've emphasised certain aspects.

Interviewer: Do you feel that you were given enough information to go on? Or would you have preferred to have more time to reflect on more questions?

Dianne: Well yes. I would liked to have gone away and thought about it and then perhaps I could have thought of some questions to ask. At the time it was all too much. And we didn't even get the chance to read the piece of paper. Not properly. It was all too much in a shorter space of time and I'd like now to have thought that we should have gone away and thought about it. When they talk about, it's not addressed as an experiment they're studying. Nobody ever used the word experiment did they, it was the 'Quasar' study. That was a bit of a blind alley really, nobody minds being part of a study but if you used the word experiment perhaps it throws a bit of a different light on it doesn't it. We didn't even think that there was any risk involved. Alright, I might have had some nasty side effects which would only be temporary....If it was offered me now I wouldn't have it (Interview 26, p6).

(Duke's C rectal cancer, married, Accounts Clerk, 57)

Dianne was adamant that the decision to have chemotherapy was the wrong decision as she experienced arduous side effects. She also expressed a deep regret that she did not spend more time considering the decision. Indeed, she felt that she was misled to believe that she was entering a 'study' rather than an 'experiment'. She also had the impression that the side effects would not be as taxing as they were. Furthermore, Dianne felt that she had a limited input in the decision-making process, and this seemed to enable her to deflect the blame for the decision onto the clinician. If she had played a more active role in decision-making, she may have been more inclined to share the responsibility more equally with the doctor.

The analysis indicates that many informants, when approaching the end of their treatment, often cannot judge whether they had made the 'right' decision due to the uncertain outcome of their illness. Others had mixed feelings about whether or not they had made the 'right' decision. Some informants felt that they had to strike a balance between tolerating the rigours of treatment, which made them doubt their original decision to accept therapy, and maintaining a positive attitude towards the treatment in the hope that it would be of benefit to them. Thus, towards the end of treatment individuals rarely assessed their decisions in very definite terms. This marked a change from the certainty with which many informants perceived the treatment prior to starting it.

Although most informants initially claimed that they had made the 'right' decision, towards the end of their treatment course their understanding of their illness and treatment had become much more elaborate. Towards the end of treatment many informants had experienced side effects resulting from the chemotherapy and subsequently learnt how to manage them. Informants had become well informed about many aspects of their illness through close contact with health care and medical staff during the six months of treatment. Although many informants interpreted the information that they were given in relation to their personal and social context, they also began to understand the complexities of the information more from the clinical perspective. Consequently, many informants tended to interpret their situation in an ambiguous way, which was often grounded in uncertainty about the future outcome of their illness. The fact that so many informants did not know if they had made the 'right' decision when approaching the end of their treatment suggests that there is seldom a 'right' or a 'wrong' decision to be made.

Role expectations in treatment decision-making

Shared or individual decision-making?

Charles et al (1998) have claimed that the breast cancer patients in their study preferred a shared approach to decision-making, in which the doctor provided the rationale behind their recommendation, and the patients reserved the right to make the final choice. Thus, the authors saw the patients as having a relatively limited role in the decision-making task. In the current study, a distinction was made between the extent to which informants played a direct role in 'decision-making' and the degree to which they participated in other activities leading to decision-making such as 'information gathering'. By making a distinction between involvement in 'decision-making' and participation in the medical 'encounter' a more in-depth understanding of the process was facilitated.

The decision-making task for the doctor and the patient involved having to decide whether or not to accept treatment. The informants' responses fell into two groups: a) those who claimed they played some part in the treatment decision-making *process* (7 out of 37), and b) those who simply followed the doctor's recommendation and trusted his or her judgement (30 out of 37). Many informants still claimed that they had made the final treatment decision even when they did not participate in the *process* of decision-making. They often recognised that the final decision was ultimately theirs. The following interview excerpts were selected as they were representative of the range and nature of responses related to this theme. The following informant felt that the decision-making task was not his responsibility since he was not the 'expert'. He expected the clinician to make the treatment decision since he had the specialist knowledge. He felt strongly that the decision-making role was the sole responsibility of the doctor, and he implied that by accepting responsibility for the decision-making task the doctor was more likely to instil a greater degree of confidence in the patient.

Interviewer: Did you find that you had a decisional role to play...?

Frank: I don't know if I want it. What's my decision? To live or die? As I said before, if you're a professional and you say that hacking my left leg off will cure that, take it off, what you're hanging about for. Get on with it. I prefer the old method of treatment in hospitals, where you went in and the bloke in charge, he knew what he was doing or at least he conveyed that impression, he wasn't going to talk to me about whether I wanted that or that. "That is best and that is what you're going to have". If it went wrong, well, it went wrong (Interview 21, p15).

(Duke's C rectal cancer, married, retired salesman, 65)

Other informants claimed that they shared the responsibility for the treatment decision. Lillian claimed that the oncologist disclosed the relevant information and advice, and told her that she had to make the decision by herself. Thus, the doctor placed the onus of responsibility for the decision on the patient.

Lillian: He had laid it all out before we went down. It was just to make up my mind, he couldn't make it up for me cos I said to him what do you think, and he said it's an awkward question because I can't decide for you. He said what we'll do, you go down and talk it over, but in the end it's you that's got to decide. We went down thinking what should I do which would be best, and all of a sudden I thought I'm gonna go ahead with it and I said to my husband, "if it was you what would you do"? He said if it was him he would go ahead with it, but at the end of the day it was my decision, so I said I already made up my mind (Interview 36, p5).

(Duke's C colon cancer, married, retired, 70)

In this case, the oncologist summarised the advantages and disadvantages of undergoing chemotherapy, but Lillian had to make the final choice to accept or reject treatment. James also felt that he was given the option to accept or reject the chemotherapy. However, what he said implied that he did not necessarily take part in the decision-making process, only in choosing to accept or reject the treatment. The distinction being that the former process involves evaluating the pros and cons of the treatment options, whereas the latter type merely involves accepting or rejecting the clinician's advice. It is evident that the decision-making task was conducted primarily by the specialist with James playing only a limited part. However, it demonstrates a shared approach to some extent in that he did make the final decision to accept the treatment.

Interviewer: Would you say that the decision to have the treatment was yours or was it the doctor's?

James: No, it was mine. They gave me the option. They can't tell you whether to have it or not, they give you the option and you have it or you don't. It's up to you. That's how I understood it. I can back out any time I want (Interview 34, p8).

(Duke's C rectal cancer, unemployed, widowed, 55)

Andrew, however, believed that it was the patient's responsibility to ask questions of the clinician if he/she was uncertain of anything. He also felt that his involvement in decision-making was limited to making sure that he understood his illness and what the treatment entailed.

Andrew: It's daft if you come out and you still don't know what's going on, then it's your fault that you haven't asked the right questions. No good being afraid of it, and not asking because it's not gonna go away, you've got to find out what's going on. Well, it was very important, it's important they should tell you what's going on, it's no good going back to the good old days when you were told to take these pills and hope for the best and if you didn't they wouldn't treat you. That's gone I hope. They tell you what's wrong, they tell you what treatment to have, that's how it should be. That's how they do it now. Even down at the doctor's surgery they tell you what's wrong....(Interview 1, p2).

(Duke's C colon cancer, married, food inspector, 59)

Andrew claimed that the decision-making task was the doctor's responsibility and not the patient's, and he felt that he needed to trust the doctor's judgement. For Andrew, the patient's and the doctor's roles were clearly defined.

Andrew: You've got to trust that people are good at their job, you know. Hopefully I'm as good at mine, and I wouldn't want anyone telling me what I might be doing. So I put myself in their hands, and you hope they're doing the best for you. So, I didn't regard uhm. I didn't feel that I ought to be going in there and deciding or helping them to decide what...how to be treated (Interview 1, p2).

(Duke's C colon cancer, married, food inspector, 68)

Many informants also claimed that they made their decision based on the oncologist's recommendation.

Interviewer: To summarise, was the decision to have the chemo yours or his?

Gene: The decision to have the treatment was mine. All the consultant done was show me the pros and cons (Interview 15, p6).

(Duke's C colon cancer, married, masseuse, 49)

Gene claimed that she made the decision to accept the treatment on the basis of the doctor's summary of the pros and cons. This indicates that the decision-making process was shared to

some extent in that the oncologist provided her with the relevant information but she actually made the final decision.

Most informants in this study preferred to be well informed and to be given a summary of the treatment options by their doctor. However, they also wanted the clinician to provide a treatment recommendation or some form of guidance to enable them to make a choice which was medically informed. This indicates that informants preferred a shared decision-making style, but one which was strongly guided by the oncologist. Thus, in most instances informants followed the advice of the specialist. One consultant claimed that the role of the oncologist is to provide advice and support to the patient.

Dr Fenton: Only ten percent of information is remembered by patients, and they may not be making a decision based on reality....My role is educational advice and also technical competence. I need to know these subjects, at the same time be a good doctor....The vast majority of patients are terrified and want to be told what to do (Interview 41, p4).

This consultant felt that he had a responsibility to advise and inform patients on the best course of action. Thus, he advocated a more paternalistic approach to decision-making. However, he also felt that patients should play a part in decision-making.

Dr Fenton: In oncology patients have a greater level of decision-making, they have more choice to choose. For instance, if they choose no chemotherapy, then that's usually reasonable....We want to reflect the changing consumerist society. Paternalism is changing (Interview 41, p5).

According to this consultant the decision-making task is a shared one, in which the oncologist provides information and advice, and the patient is given the option to choose regarding treatment. Similarly, one of the senior registrars believed that it is the clinician's responsibility to make sure that patients understand the information which they are given.

Dr Smith: Patients have got to understand what they're agreeing to. A patient may have preconceived ideas of what treatment will involve. You have to discuss with patients on the best option. Psychological overlay and their preconceptions of treatment are important to understand (Interview 42, p6).

It is clear that this oncologist felt that the decision-making task should incorporate the patient's views into any dialogue. So, even though the above oncologists felt that their task was largely a

technical one, they also felt that the patient's preferences were important to consider in the decision-making task. Thus, the decision-making process required a judgement that involved the clinician's, as well as the patient's, perspective. Similarly, most patients felt that the decision-making process should be shared to some extent, but that it should also include an exchange of information between the doctor and the patient.

The findings presented in this section suggest that the oncologists perceived their role in decision-making to be concerned with reaching an understanding with the cancer patient and sharing the responsibility for the decision. Likewise, most informants in the study preferred the oncologist to provide a recommendation and to explain the facts to the patient (refer to part II of this chapter). This suggests that the communication process between the patient and the oncologist does not necessarily impair the involvement of the patient in the decision-making process. However, in areas of medicine where outcomes are perhaps more predictable and defined, the role of the patient in decision-making could be restricted somewhat. One of the oncologist illustrated this point:

Dr Fenton: Decision-making here is not like what's involved in deciding whether to have your varicose veins done. Since chemo probably helps but we don't know how good it is. In terms of curing patients we have a very long way to go (Interview 41, p5).

This doctor claimed that the decision-making task in oncology is more complex than in other areas of medicine, which may not require the patient's involvement. Therefore, in the case of treatment for varicose veins the decision-making task might be more straight forward than is the case in oncology.

The role of family and friends in decision-making

The findings so far have indicated that most informants preferred to share the responsibility for the treatment decision with the oncologist. Consequently, many decisions involved a deliberation between the patient and the clinician (refer to part II). Often, this process of deliberation did not end at the consultation. Many informants continued to evaluate the choices that were made with friends and family. In most instances, this process of 'evaluation' involved asking others whether they agreed with the decision that had been made. Informants felt they needed further approval from their friends and family as assurance that they had made the right choice. In 28 out of 37

interviews informants discussed the treatment decision with their friends, relatives, and/or other cancer patients undergoing similar treatment. The remaining 9 informants did not discuss the treatment options with others, either because they did not want to worry them or because they had firmly made up their minds about what to do. The following informant wanted advice from a friend who had previously undergone chemotherapy for breast cancer, and who consequently reassured him that he had made the right decision.

Graham: A very, very good friend of ours, another woman who is a single parent, and about two and a half years ago she had breast cancer. And so when this thing came up the first person outside Sarah (wife) I talked to. You know straight away had her feet on the ground, dismissing all the wild fantasies that I had. She's saying don't be a silly old bastard, and has really been a rock. I mean Sarah, bless her, tends to get a bit emotional about it you know, thinks I'm suffering like hell (Interview 17, p. 6).

(Duke's B/C colon cancer, married, retired Fire Brigade Chief, 63)

Graham's friend managed to put his fears at rest and provided a more objective opinion, which he found helpful. He took part in a dialogue with his friend who helped him to keep a much more positive view of the chemotherapy treatment.

Graham: I said to Jill if my hair turns green or it falls down they can stuff their treatment. Don't be so bloody silly she said, you're better off bald than bloody decaying. She brings a fairly pragmatic approach. Lets face it, all of us are entitled to feel sorry for ourselves very occasionally, and it's important I think to have somebody who sort of pricks the bubble of it, otherwise you get low.

Interviewer: Those are the practical things you discussed with Jill. It wasn't a question of should I have this treatment, but you already made your mind up?

Graham: Well I'd said to her I think I'm gonna have the treatment. She said yes, bloody right you ought to have it. It was so funny because we went out to lunch the day after I've been at the Oncology Centre and we were talking about her examination. Jill had been explaining a number of people who had examined her in the course of her treatment, and she said you know she said, after about three months she said I felt as if everybody in Bristol had been on the end of my bloody boobs. I just thought it was funny. There's a lot to laugh about (Interview 17, p7).

(Duke's B/C colon cancer, married, retired Fire Brigade Chief, 63)

Graham feared the prospect of experiencing hair loss, but his friend reinforced his need to accept the offer of treatment as it could increase his chances of survival. She placed the possibility of hair loss in context by indicating to Graham that the side effects were a small price to pay for a longer life. Frank, however, was very frightened about the prospect of chemotherapy. He actually refused the treatment at his initial appointment with the oncologist. Having talked things over with his family he finally decided to accept the treatment.

Interviewer: So you kind of said I'm not making any decisions because of the way you were told?

Frank: That's right. I knew damn well that once my wife started talking to me about it she'd want me to have it. I knew the family would. I knew that once I got out of the room I'd cool down and things would change, and I'd say right well I'll have it. I suppose my sons logically approached the fact alright, 'when are you gonna start?' Not 'are you?', but 'when'. My whole family were like that, 'when you gonna have it?'

Interviewer: What about your wife?

Frank: My wife said to me, the decision is yours but I hope you take it. She wants me to live. We're back at chance again - Survival (Interview 21, p10).

(Duke's C rectal cancer, married, retired salesman, 65)

Initially, Frank felt that the oncologist was too 'coercive' during the consultation. As a result, he rejected the treatment as he felt that he was not presented with the freedom to choose and to make his own decision. Having discussed the matter with his family, he realised that he had to accept the treatment option. Thus, the decision to accept the treatment was finally reached through a process of negotiation with close relatives. Other informants felt that talking to other cancer patients reassured them about their decisions.

Ann: I was talking to a man in the Oncology Centre and I felt really good after I'd spoken to him because apparently because he'd been to his doctor just before Christmas with what he thought was sinus trouble and chest complaints, and the doctor told him he had a tumour here (on the throat), and they gave him three months to live. He had chemotherapy and now he's on radiotherapy and he said it's all cleared. He drives to Taunton and back and goes cycling in the evening. He's fifty two. I thought it was wonderful. It makes me feel good to hear a story like that, if they can do that for him that's wonderful. It's got to be partly positive thinking. You have to go along with the treatment and be positive (Interview 18, p4).

(Duke's C recto-sigmoid cancer, married, complementary therapist, 66)

Interviewer: Going back to your first time at the Oncology Centre, what kind of expectations did you have? I remember you said you didn't know what to expect?

Derek: I really didn't know what to expect. I had been to see a friend of ours who'd been going for chemotherapy five years ago, she just started again, and she said there is a total difference in her five years, improved no end she said. I know you haven't experienced it before, but she sort of put me at ease (Interview 23, p21).

(Duke's D colon cancer, married, retired Managing Director of Export Company, 71)

Ann and Derek found it very reassuring to talk to other patients who had undergone chemotherapy and who seemed to have recovered completely. Thus, the discussions that both informants held with the other patients enabled them to feel more positive about their decision to undertake treatment. It is evident that most informants found it very helpful to obtain further reassurance that they had made the best decision. The process of decision-making continued beyond the immediate encounter with the oncologist, whereby the informants often felt that they needed to embark on a re-negotiation and re-evaluation of the treatment decision.

Information needs

'Honesty' and the negotiation of information

Much of the literature on the doctor-patient relationship indicates that most people expect their doctor to be honest with them, even when disclosing 'bad' news (Fallowfield, 1993; Miyaji, 1993). For individuals with a cancer diagnosis, the truth can often mean having to come to terms with a poor prognosis and ultimately with death. However, there is little understanding of the way in which cancer specialists communicate the 'truth', and more importantly, *what* they regard to be adequate and truthful disclosure. The findings in this study suggest that the extent to which 'truth'

is disclosed is often the product of a 'negotiation' or a deliberation between the doctor and the patient.

As mentioned previously, the communication process between the oncologist and the patient is often laden with 'obstacles'. As the decision-making task involves the interpretation of 'ambiguous' and 'probabilistic' information, the disclosure of 'truth' may be inappropriate if not impossible, since it requires a value judgement. For instance, the following interview extract with a consultant oncologist supports this point.

Dr Fenton: With a treatment which will cure you, the decision is easy. But when there's only a ten percent chance of cure and when costs are greater then that's much more difficult. If you're seventy or eighty, then it becomes a value judgement, which is more difficult for doctors to make (Interview 41, p4).

This passage suggests that it is difficult to make decisions in oncology purely on the basis of scientific evidence and clinical judgement. The level of uncertainty involved in decision-making means that the disclosure of the full 'facts' may be unattainable as the boundaries of 'fact' and 'opinion' often intersect. Similarly, a senior registrar in oncology also indicated that it is inappropriate to talk in terms of 'truth'.

Dr Smith: I may not tell the whole story, and I won't tell them the prognosis unless they ask because you don't know. You have to be sensitive with patients....So I can't be forceful to say they need it (the treatment) as I don't know if they need it. It's important that patients understand the benefit of treatment and that the doctor doesn't know (Interview 42, p10).

Much of what is disclosed to the patient is shaped by the uncertainty surrounding the outcome of treatment. Thus, as Dr Smith claims, it is important for the doctor to admit her uncertainty to the patient, especially in the disclosure of prognoses and in circumstances where treatment benefit is unclear. It is evident from this narrative that the extent to which a doctor can reveal the complete picture to the patient is greatly influenced by the availability of information. In these circumstances the patient's opinion can facilitate the decision-making task. In 22 out of 55 consultations an 'active' negotiation or deliberation took place between the oncologist and the patient (please refer to Part II of this chapter). The following dialogue between a consultant and a patient illustrates how a decision was reached through a process of 'negotiation' and 'evaluation'. This extract of a consultation is representative of the type of 'active' decision-making

negotiations which took place during this study. This was a conversation between Dr Smith (senior registrar) and a 70 year old, male patient.

Dr Smith: We're in a sort of a grey area where it's possible a few seeds were dropped.

Arthur: It's pretty good?

Dr Smith: Yeah (said without conviction). There are two options. Either we do nothing or we give chemotherapy in case it's spread. Unless we chop you up there's no way of knowing if it spread.

Arthur:...Well I'm 70, what are the odds of curing me? You just gave me the answer. Let it go on.

Dr Smith: All we can do is give you the stats, as we don't know. We grade cancers, you are a C.

Arthur: Aah a C's a bad one.

Dr Smith: A's if it's small, B if it's gone through the wall. You're a good C. If you take group C overall I can tell you what a group of 10 men can live up to five years.

Arthur: Tell me.

Dr Smith: Three. With chemotherapy we can get it up to four out of ten. What would you like to do? Contemplate chemo or leave all alone?

Arthur: Do you think I'm wrong to do that-leave alone?

Dr Smith: No, I don't. If you should agree to the study we would randomise you to treatment or no treatment. In your situation we don't know if chemo's of benefit.

Arthur: Is it worth it?

Dr Smith: I don't know.

Arthur: I don't feel that bad. I don't feel like a man any more. Makes me wonder whether it was worth having the operation done (Observation 5, p1).

(Duke's C rectal cancer, widowed, retired aerospace manager, 70)

This patient later decided not to have any treatment. The narrative demonstrates how a decision was reached by means of a 'negotiation' to evaluate the benefit of pursuing the treatment option. The oncologist reveals to the patient that the benefit of chemotherapy is uncertain in his case, so the patient interprets this uncertainty as a cue to refuse the treatment. Initially, he implied that he was too old to have treatment, and later expressed his reservations about chemotherapy when the clinician claimed that it would only increase his chances of survival by ten percent. Finally, towards the end, the patient claimed that he did not "feel that bad". The clinician's approach was quite 'neutral' as she gave an objective summary of the evidence. When the patient asked the doctor if she thought that refusing the treatment was wrong, the doctor responded that she did not think that it was the wrong choice since the evidence was uncertain. Although the doctor was honest in her disclosure of the 'facts', she was unable to provide the 'complete' information to the patient. The speed with which this patient decided to decline the offer of treatment indicates that he may have had reservations about the chemotherapy prior to the consultation.

A distinction between 'honesty' and 'truth' can be drawn when examining the data. Although, most doctors in the study felt that it was important to be honest with patients, they also felt that 'facts' were open to interpretation in oncology. The findings show that information and decisions were evaluated between the doctor and the patient. However, according to the patients it was the perceived honesty of the oncologist that enabled them to participate in the 'negotiation' process. For some patients honesty was an important prerequisite for dialogue with the clinician, and for enabling them to take part in decision-making. Other informants felt that honesty was crucial for the maintenance of trust between the oncologist and the patient, which in turn facilitated any 'negotiations' that ensued. The way in which 'honesty' enabled patients to embark on 'negotiations' with the oncologist is illustrated in the following interview narratives. The following interview episodes illustrate the importance of honesty for the informants. Out of 37 informants 27 claimed that 'honesty' was central to the maintenance of trust between the doctor and the patient, and in helping patients to return to a more 'normal' life. The remaining 10 informants did not explicitly state that honesty was important but most implied it.

The interview narratives selected in this section were representative of the range and nature of responses provided regarding the 'honesty' theme. The first interview passage illustrates how honesty strengthened the informant's relationship with the oncologist by 'releasing' the flow of information between them.

Interviewer: Do you find that the communication is better?

Eileen: Much better because he's not afraid to tell you anything and you're not afraid to hear it so it makes it much better. It's like by the

end of the six months, it's like the oncologist when he was going round about trying to tell me about the x-ray and I could see that he just didn't know how to tell me. And then my daughter said, "doctor if there's anything to say, tell us" And he looked at me and said "do you want to know"? I said "definitely". From then on things were easier, a lot easier for the doctor and myself (Interview 24, p9).

(Duke's C colon cancer, retired school caterer, widowed, 61)

For this informant, openness was essential in breaking down any barriers that may have existed initially between her and the oncologist. The informant claimed that honesty enabled the clinician to reveal all the information to her, and similarly, she felt more confident in her ability to communicate more freely with the doctor. In turn, this freedom of communication fuelled their ability to 'negotiate' a satisfactory treatment decision.

The following informants wanted the doctor to be honest with them so that they were aware of where they stood. They wanted to know if their disease was terminal so that they could make plans with the time that was left.

Interviewer: If I can ask you, what qualities do you expect in a doctor?

Reginald. Honesty. I'd far rather a doctor told you he didn't know. If you asked a doctor a dodgy question and he didn't know the answer I'd far rather he said I don't know but I'll try and find out than he gave you a load of bull.

Interviewer. Why do you want honesty in a doctor?

Reginald. Well, you know where you stand (Interview 9, p17).

(Duke's C colon cancer, single, retired Factory Worker, 79 – Has Parkinson's Disease)

Interviewer: Would you had preferred to been told before by the surgeon that you had lymph node involvement? (The surgeon did not inform him prior to referral to the oncologist that he had several lymph nodes that were infected with cancer).

William: From my own point of view yes. I like to know what's going on. I don't like this idea of saying a little bit and then you find out it's something different later on. They did tell me in fairness to the surgeon and his team. They did say they thought it was malignant right from the very beginning which I was quite happy about. I'd rather it was than somebody who turns round and says oh well it's nothing to worry about and then you find that you got what you weren't expecting. I like to know what's going to happen.

Interviewer: That's very common. Thirty, forty years ago doctors didn't really tell patients as much, "you just do what I say kind of thing". Now they're more likely to tell you everything. Do you think that is a change for the better in your case?

William: In my case yes. I can understand that some people, you get these nervous individuals that you worry the life out of them. If it's coming it's coming. There's nothing else you can do about it. I'd rather know what's going to happen. If I had six months to live I'd rather be told about it. I should be able to put myself together for the next six months, get things tidied up. But I don't like this idea of being kept in the dark (Interview 2, p11).

(Duke's C rectal cancer, widowed, retired Plumber, 70 – This man was born in Jamaica where he lived most of his life)

Reginald and William preferred to know the truth about their illness so that they could plan their time in view of the fact that death could be imminent. Also, being honest reduced the possibility that patients received unexpected information. Thus, for these two informants truthful disclosure of information was essential in enabling them to organise their lives to its full potential. For the following informant honesty also empowered her to make critical choices about her own care.

Interviewer: Do you find that the honesty of the doctor has been beneficial to you?

Jean: Yes, yes it suits me, definitely suits me, my personality you know that's me. I want to be in charge of me. This is the thing with the chemotherapy, I wanted to be able to say "yes I will have it" you know. As I say, all my family said "you really must have it mother, you must have it". In the end I said well, "I'm having it for you", I wanted to make the decision. So telling me all the truth was absolutely essential really, I mean you have to know otherwise you can't make the decision can you if they're covering something up? (Interview 11, p6).

(Duke's D colon cancer, married, retired teacher, 68)

Her perception that the doctor was telling her the relevant information truthfully was essential in enabling her to 'negotiate' the decision with the doctor, and ultimately to make the final decision by herself. She felt that it was up to her, and not the oncologist, to make the final decision regarding her treatment. For many informants 'honesty' and the provision of relevant information went hand in hand. It was not enough for the oncologist to appear to be honest, the informants often wanted to be as fully informed as possible.

Interviewer: Would you lose trust in the doctor if he didn't explain to you the situation?

David: It would damage your trust if I didn't know what they were talking about. If you realise that he kept it from you to soften the blow to you or something, then you'd be worried why you're doing it. If there's a logical reason behind why he's doing it then fair enough, but if for some reason he's saying something to you which you can't really see why he kept it from you, then I'd be a bit more upset about it (Interview 35, p7).

(Duke's D colon cancer, married, retired Local Government Officer, 64)

This informant strongly believed that honesty was essential for maintaining faith in the clinician. Thus, the need to understand the purposes and the consequences of treatment was a precondition for the maintenance of trust in the doctor. Luhmann (1979) contends that the lay public is relinquished of its responsibility to understand 'expert systems' (institutions such as hospitals or financial corporations) as technology advances since 'expert' knowledge is too complex for them to grasp. Consequently, decision-making is left to the specialists. However, the above interview narratives suggest that some individuals are unlikely to place complete faith in 'expert-systems' with which they have contact. Contrary to Luhmann's assertion that the lay public is passive in its interactions with 'experts', the findings strongly suggest that cancer patients are often active in their pursuit of ('technical') information. More significantly, many informants in this study claimed that they did not just participate in decision-making, they also expected their clinician to be completely honest with them.

The need to reach a consensus in decision-making is the primary objective of the patient and the oncologist, and this is often accomplished through a process of 'negotiation'. The way in which information and clinical 'facts' are presented by the clinician can strongly affect the nature of this 'negotiation' (see part II of this chapter). The evidence from this study shows that patients hold firm expectations of their specialist and of their care. Also many still participate in the treatment decision-making process even when they appear passive during the consultation. For example, they may consult friends and family outside of the medical setting. However, there were some cases where patients did prefer to leave the final decision entirely to the oncologist.

‘Reassurance’

As shown previously, informants wanted to keep a positive attitude in the face of uncertainty and reassurance was important in enabling this. Although most informants preferred their clinician to be honest with them, they also wanted the doctor to provide reassurance to help them cope with their affliction. However, the task of reaching a balance between being honest and providing reassurance could sometimes prove difficult for doctors. Therefore, many informants often tended to draw on positive nuances and comments expressed by clinicians in order to reinforce a more positive view of their illness. Such reassurance, which some informants received from friends and family, as well as from medical staff, often influenced the final treatment decision. Out of 37 informants 32 claimed that they wanted to feel reassured by their oncologist that they had made the best decision, and that they had been given as much information as possible about their condition and its treatment. The interview excerpts in this section were selected because they were representative of the range and nature of the responses that were provided by informants as a whole regarding this theme.

Ann, for instance, expressed a strong desire to feel positive about her situation. She also felt better in the belief that she must have a good chance of ‘beating’ her disease because otherwise she would not have been offered the treatment.

Ann: People who are on trials can be fifteen percent better than people who are not on trials, and when she said all that she said I think you're about eighty percent there. You just need a [tweak] from the chemo and you should be OK, which I thought was a lovely and reassuring way of putting it. So I phoned up yesterday, I left a message to say I would like to be involved in Quasar on grounds that this therapy does [work]....So you do get extra care and people flourish, so that woman then contacted that woman who was very important to me, and I labelled going to Quasar very much more positively. I didn't feel I was just a sausage in a sausage machine. Far from being just shoved into it, there was a selection process and I'm considered to be a good enough bet to spend their resources on. So that's made me feel much more comfortable about it (Interview 18, p2).

(Duke's C recto-sigmoid cancer, married, complementary therapist, 66)

Ann made a decision to accept chemotherapy largely because the oncologist reassured her that the treatment would benefit her. She was also told that patients who were entered into clinical trials received better care, and this made her to view the treatment in a more positive light. Ann's emphasis on the benefits of undertaking chemotherapy suggests that she viewed the decision to accept treatment as a very positive step in her recovery.

Another informant felt that reassurance was vital in enabling him to cope psychologically with his illness.

Frank: The good things they should keep pumping because they help you, the benefits outweigh the rough stuff. Who's worried about diarrhoea when you're talking about your life? Who worries about sore gums and things like that? You could possibly leave it til later on and as soon as 'they' start coming up in the treatment they say that's a possible side effect we got a tablet that will stop almost anything except the London train. That first meeting is most important because people are terrified. You got to have it to go in there and really feel it (Interview 21, p10).

(Duke's C rectal cancer, married, retired salesman, 65 – Jahova's Witness by religion)

The informant felt that constant reassurance from the doctor was essential in helping him to keep a positive attitude. He felt that honesty was important, but it was equally important for clinicians to 'empower' patients with support so that they were confident in their decisions. For Frank, the need for reassurance was essential in helping him to cope with the uncertainty and fear surrounding the initial meeting with the oncologist. Other patients wanted to feel that help was there when they needed it. Some informants claimed that the perception that they were being cared for, and that something was being done about their disease, persuaded them to accept the chemotherapy treatment. Indeed, despite the prospect of undergoing six months of debilitating treatment, it was often considered to be a necessary and a positive step on the path to recovery.

Interviewer: Are you happy with the decision which was made?

Peter: Yeah we are.

Wife: And the fact that if we do have any doubts, help is there twenty four hours a day (Interview 37, p7).

(Duke's C recto-sigmoid cancer, married, electrical engineer, 53)

Other informants felt that the more they learnt about their illness, the more confident they felt.

Terence: In my case it has because everything that's happened to me so far has been reassuring. It's been caught in time, I've got an eighty percent chance it won't come back and all that sort of thing. So all that's very reassuring. If I gone further down the road it might be different. When you're told that you're facing something that might kill you, it comes as a shock at first, obviously. I found that the more I've

been told about it the more I've learnt about it, what the chances of success are and so on. That's helped me considerably. It helped me keep a positive attitude towards the whole thing and made me optimistic instead of pessimistic (Interview 29, p10).

(Duke's C rectal cancer, married, retired Police Officer, 60)

This informant believed that as he learnt about his condition, he felt more positive about tolerating the chemotherapy treatment. A better understanding of his illness and treatment enabled him to accept the treatment option with a greater degree of confidence that he had made the right choice. Also, the decision to undertake the treatment enabled the informant to feel much more positive about the future outcome of his illness. Thus, some informants were able to cope more successfully with their diagnosis as they gathered more information. Certainly, an adequate supply of information was regarded as vital in helping patients feel reassured about the decisions that they had reached.

Interviewer. How much did he inform you about that, not necessarily just about the treatment but about how you are and...?

Tim. Yeah, I think I probably would have preferred a bit more information. I mean he told me broadly that I've got cancer of the liver and ahh, and to try and prevent from progressing any more.

Interviewer. If you want to know certain things would you like to be told or would you like the doctor to be less forward in telling you?

Tim. No I think, I think I wouldn't mind being told. I would like to know where we're at and what the situation is and the way forward and so on. And if it doesn't lie in cancer therapy or that side of the department it's quite important to know what I should do (Interview 5, p15).

(Duke's D colon cancer, married, Pharmacist, 58)

Interviewer. Can you tell me anything about whether you were happy about the sorts of information you were given?

Ray. We got all the information we needed. They went out of their way to explain things to you, you know, so.

Interviewer. Perhaps looking back you think you might wanted to have been told about...?

Ray. I'm confident about that, you know, they explained everything to

you very fully.

Interviewer. Right. Is there anybody else who was involved in helping you understand that your treatment?

Ray. No, not really. Because they explained everything pretty fully, you knew what to expect. In fact when I came home from hospital I knew exactly what was going to happen. Because I've been told what's going to happen (Interview 3, p5).

(Duke's C colon cancer, married, has own building company, 68)

Tim wanted to feel reassured by the clinician that everything possible was being done to 'fight' his disease. He also wanted to be told how he could become involved in this 'fight' as a way of exercising some degree of control over his illness. Tim wanted to know that the best was being done to suspend the progression of his disease, and the best way that he could cope with his illness was to be well informed. Ray felt confident that everything was explained fully to him about his treatment and illness. He felt that he knew what to expect which made him more relaxed about the decision that he made to accept the chemotherapy. Other informants, however, felt that an element of 'discretion' in disclosing the full facts to certain patients who are terminally ill is desirable, so that they can enjoy the remaining time that they have left without the explicit knowledge that they are going to die. Thus, in certain circumstances withholding 'bad' news rather than disclosing the full facts can benefit some patients.

Linda: I mean I'm single, ok I've only got two sisters. If it's a person, say I had two kids and a husband it might be different in that situation, it might be best for her not to know because of the kids and things. I don't know. I think if you were very old, I can't see the point of telling them. If they're dying of cancer I can't see the point of giving them the upset saying it's best that we don't operate – "it's a good chance that you'll get through" - and let them have peace of mind. I think that everybody's going to be different aren't they. I can't see the point of telling an old person that they've only got so long, you might as well give them the hope that they're gonna get better. Whatever anybody says, it's a death sentence. It's like having a noose put round your neck waiting for it to be dropped, it is. It is scary. I mean everybody's going to die but when it's set out for you it's not as nice (Interview 19, p27).

(Duke's C colon cancer, single, property developer, 55)

One of the most common reactions during the first encounter was fear caused by the uncertainty of not knowing what to expect from the meeting. Many patients were reluctant to participate during their first encounter with the oncologist, simply because they did not know what to expect

and how to take part in an open dialogue with the clinician. Greater 'reassurance' from the doctor often facilitated a greater level of engagement in the interaction, and made them feel more confident about the decision that was reached.

Continuity of information

Chemotherapy treatment usually lasts up to six months. During this time, the process of making decisions continues whereby patients are partly responsible for managing their own symptoms, diet, and wellbeing. This often involves frequent (self)-reassessment and examination. Under these circumstances it is vital for patients to have a good understanding of what to expect from their treatment, and more importantly, how to manage and re-evaluate their health. Throughout the treatment course patients often need to adapt to new situations which involve frequent 're-negotiations' with the oncologist. During the course of having treatment many informants required access to information which could cast some light on the symptoms that they were experiencing. Out of 28 follow-up interviews 24 informants wanted to be given information on a continuous basis throughout their illness experience to inform them of their progress.

Jean: When you talk to a doctor, or even the nurses, you tend to forget, "now what did they say about that"? But if you've got a book with it all written down you can refer to it and go back to it again. And then when something happens and you feel something, it tells you.... I've read them all, and you can go back and refer because it is in black and white. If you ask the doctor it's fine, he gives you the right answer at the time, but later you're thinking about it and you can't remember what they said.... If you got something wrong and you read that and they tell you that this is going to happen and this is all part of the treatment, it reassures you that there's nothing gone wrong, if you feel a particular sickness. It all tells you in there that you may not feel this or you will feel this or something, and then you realise that it's all part of the treatment (Interview 11b, p5).

(Duke's D colon cancer, married, retired teacher, 68)

For this informant, the need to feel reassured during treatment was important especially because there was confusion whether the symptoms were the result of the treatment or the illness. For most, the treatment side effects can be very confusing especially because the symptoms experienced by the patient frequently varied. Jean felt that the patient information sheets enabled her to reference any problem or ailment that she was experiencing, and this enabled her to

understand and manage her symptoms. Other informants expressed a desire to understand the likely treatment side effects that they could expect to experience in order to prepare for their impact on themselves and their families.

Terry: Because a patient doesn't want to be left in ignorance. Not only the patient, the patient's family, husband and children, they want to know that the patient is in good hands, and not be fobbed off....As I say, we are all human beings, we want to know what's going on. You need to be told in simple terms so you have some grasp of what will be done and what the effects are going to be. Because he may be putting a big burden on his whole relation with his family. I think you should be informed of what's going to happen. What they're going to do, what they're hoping to achieve, and what the end result could be. What happens due to the treatment should also be explained, like side effects (Interview 33b, p3).

(Duke's B/C colon cancer, married, retired aircraft engineer, 73)

Terry wanted to understand the side effects that could result from the treatment, as that could influence the nature of the 'after-care' that he would receive. Other patients were keen to understand precisely how the treatment was affecting them, in order to strengthen their confidence that they were winning their 'battle' with cancer.

Ann: One of the things I was very surprised about was to find that the blood tests don't tell you whether the only cancer that does show up in the blood is leukaemia which is a cancer of the blood. But any cancer which is brought by the blood to other sites doesn't show up.... I said to him (the doctor) I haven't got my results, and he said "yes I had to ask for them", and I said I would like them. He didn't volunteer to give me the information. He gave it to me but when you have the blood pressure taken they never volunteer. I always say "what's my blood pressure", and there was a staff nurse at the hospital who said "there there dear don't worry about it"- "what's me bleeding blood pressure missus?" I think that with that sort of thing, they will give it to you, but you'll have to ask, they don't think it's part of their job to educate you. And my blood pressure was better on all fronts, better than when I started (Interview 18b, p8).

(Duke's C recto-sigmoid cancer, married, complementary therapist, 66)

Ann wanted to be informed of her blood count as a way of understanding her progress in treatment. In her view, the results of blood tests provided her with 'hard' evidence of how her body was coping with the treatment. Another informant, Lillian, wanted to be given accurate information about her cancer and its progression in order to avoid confusion and prevent the disclosure of conflicting information to her family.

Lillian: The hospice nurse, my son said to her is my mother dying, and she said yes. So when they did get to the hospice so they wanted to know what was going on, and they were very good to them there. My oldest son wanted to know because they've all been hearing different versions. And they did put them right there which is wonderful really. Our own doctor at the time we weren't getting anywhere with him. At the hospice they explained to the children everything. My own doctor didn't even come down. We can't find out who from they were given the different versions (Interview 36b, p13).

(Duke's C colon cancer, married, retired, 70)

Often individuals did not simply want reassurance with words but also with some 'evidence' or 'proof'. Again, the process of obtaining reassurance from the doctor seemed to be a process of 'negotiation'. Even when informants played a limited role in the interaction with their doctor, they often held definite expectations of the type of information that they desired. Most informants required a continuity of information throughout the duration of their treatment cycle. The following dialogue between a 55 year old patient and Dr Fenton, (consultant clinical oncologist), provides an example of such a consultation.

Linda: After the last one I got very depressed, but it's because it's going towards the end. That's scary because...that's on my mind now. I'm worried now that I'm going to be told "whooff".

Dr Fenton: The worst time people have is at the end of treatment, coping side.

Linda: It's peculiar because you're having some hope but towards the end...

Dr Fenton: You can have some counselling.

Linda: No, it's no good. It won't help.

Dr Fenton: Counselling won't tell you if you'll be alive or dead, it's to make you feel better.

Linda: You don't think it'll help me do you?

Dr Fenton: (The doctor smiles as if to say no)....

Linda: What chances do you think I've got of being cured?

Dr Fenton: You had a 5cm tumour, which went through the full thickness of the wall and 3 out of 12 glands were clear. You had the op

and it's 50/50. The first time you looked awful. We wouldn't put you through all this if we didn't think.....

Linda: I feel better (physically). People say I'm going to be alright. How do they know I'm gonna be alright.

Dr Fenton: I think you're doing alright.

Linda: It frightens me to death stopping that chemo.

Dr Fenton: You're on the home straight now, picking up.

Linda: You think so? Shall I have a scan?

Dr Fenton: It's not something I would normally do.

Linda: Could I do it privately?

Dr Fenton: Yes.

Linda: Would it be reasonable to have it here?

Dr Fenton: Yes. The scan would not show anything. We usually do one after a year.

Linda: I'd love to know.

Dr Fenton: I'm quite happy to do it if I thought it would help (Observation 25, p1).

(Duke's D colon cancer, single, property developer, 55)

This lengthy passage from a conversation between a patient and an oncologist illustrates the 'strategies' that the patient used in order to reassure herself about her illness. She claims that she was anxious about the outcome of her therapy, and she rejected the clinician's recommendation that she should see a counsellor. Her main worry was situated in the oncologist's inability to inform her with any degree of certainty that the treatment had been effective, and as a result she offered to pay privately for a scan in the hope that it would allay her fears. There is certainly an indication that for many patients, alongside the need for emotional reassurance, there is also a need for some clinical or scientific 'evidence'. For instance, this patient expressed a concern about the outcome of her treatment, and towards the end of the meeting the oncologist attempted to allay the informant's fears with assurances that she was getting better. Clearly, this patient

wanted to maximise her use of the medical information available as a way of strengthening her confidence in the outcome of her treatment.

Charles et al (1998) found that breast cancer patients interpreted scientific information in a way that made sense to their everyday lives. They also found that complex information was usually re-interpreted by patients in a different way to that intended by the doctors. The authors concluded that a balance should be reached between promoting scientific accuracy in communicating clinical information to patients, and helping patients to maintain a positive attitude towards their illness and treatment. Although, they did not suggest what that balance should be. The findings in the current study also suggest that patients interpreted scientific information, partially, in a way that made more sense to their everyday lives. However, as scientific information is often open to interpretation, a greater degree of 'reassurance' by oncologists could serve to reduce patient uncertainty.

The current study indicates that many colorectal cancer patients are comfortable with a limited involvement in the decision-making process, as often they do not feel that they have a 'real' choice. These findings indicate that more emphasis should be placed on providing information and reassurance to patients. This may in turn, equip them with the confidence and ability to understand the choices that are available to them regarding treatment.

‘Social circumstances’ and decision-making

Social class and employment status

Some authors have raised the importance of family composition on decision-making behaviour (Yellen and Cella, 1995). There is the belief that social class plays an important role in the decision-making process, whereby educated and articulate consumers of health care are more likely to play a more commanding lead in this process. However, in the area of cancer care most research has been conducted on women with breast cancer. In the case of breast cancer, women are more likely to be well informed about the treatment options due to the greater attention that this condition has received in the media. Also, breast cancer predominantly affects relatively young people who might be more educated and better informed. In contrast patients with prostate and colorectal cancer tend to be older and may be less well informed. For this reason, the impact of social class on decision-making has not been adequately investigated. In order to address the impact of social class on decision-making in cancer care, it is necessary to study a diverse group of patients from different social positions. However, in the current study the informants did not represent a very diverse group of people. Most tended to be retired and had in the past worked in ‘manual’ or partly manual occupations. Only a small number of informants held, or had previously held, ‘professional’ jobs, which makes meaningful comparison difficult. Consequently, the analysis found no social class differences in the responses of the informants involved in this study.

The interview sample consisted of people who were largely employed in ‘blue collar’ occupations such as factory work, school catering, and contract cleaning. There were 5 factory workers, 5 caterers, 7 clerical/ office workers, and 14 people working in skilled manual occupations such as skilled technicians and ‘lower level’ managers. The remaining 6 people could be classified as working in professional occupations. They comprised one social worker, three engineers, one company director, and one pharmacist. No significant occupational class differences were identified in respect to decision-making during the analysis of the interview and observation data.

The analysis did indicate that employment status had some bearing on decision-making. Most of the ‘younger’ informants (those under 60) were in full-time employment. Conversely, most ‘older’ informants (those over 60) were either semi-retired or retired. Most of the ‘younger’ informants perceived the chemotherapy or radiotherapy treatment as a means of returning to their usual way of life which in many cases meant going back to their jobs and resuming their everyday

roles. Their roles were often closely tied up with their work and domestic responsibilities, especially to their children and spouses.

Family composition

Irrespective of age, many informants made decisions ‘on behalf’ of their family, and at other times it was their family who influenced them to take a certain course of action. In 24 out of 37 interviews family composition influenced the treatment decision-making process.

Yvonne, a 37 years old Social Worker who is married with three young children claimed that her main reason for undertaking palliative chemotherapy treatment was to enhance her survival chances for as long as possible for the sake of her children.

Interviewer: What role did your family play in helping you to make a decision about your treatment?

Yvonne: Well, it's more the children because I had to ask if I wanted the actual chemotherapy. It was my decision, but I had to have it because of the children, I mean there was no questioning that. So I said to the oncologist I got to have it because I got young children, there was no questioning (Interview 7, p14).

(Duke's D colon cancer, married, social worker, 37)

Angela and Frank claimed that their close family encouraged them to undertake the chemotherapy, even though they themselves were initially uncertain about whether they should have the treatment.

Interviewer: You left the consultation with the oncologist without making a decision. How did you come to a decision?

Angela: Because my family kept on saying go ahead to have it done really. Because they were a bit worried, especially my daughter who worries because she was at the hospital for ten days (Interview 25, p7).

(Duke's C colon cancer, widowed, retired, 74 – Italian)

Frank's family also encouraged him to accept treatment.

Frank: I knew that once my wife started talking to me about it she'd want me to have it. I knew the family would...I suppose my son's logical approach sums it up. He said "when are you going to start?" Not "are you" but "when?" My whole family were like that, "when you going to have it"?" (Interview 21, p13)

(Duke's C rectal cancer, married, retired salesman, 65)

For Yvonne, having young children was the main consideration in reaching her decision regarding chemotherapy. However, in Angela and Frank's case it was the presence of close family support, and the availability of relatives, which helped them to make a decision regarding treatment. It is evident that it was not simply the patient's desire to get better which propelled them towards accepting treatment. In many cases their close family played an active part in helping the patient reach a decision, usually to accept the treatment. Brenda claimed that she wanted to stay alive as long as possible for her family. Her family was the main reason why she decided to undertake six months of palliative chemotherapy.

Brenda: Well you think about your family. I mean we have children and grandchildren and I want to be on this earth as long as I can. That's the general thing. I'm not ready to go yet you know. I'm not going yet, and the quicker we get on with this (treatment) the better. I think that was my general attitude (Interview 8, p14)

(Duke's D colon cancer, married, retired domiciliary worker, 66)

Joan was encouraged to accept the radiotherapy treatment because her son had the same therapy for testicular cancer from which he has now fully recovered. She thought that if her son benefited from the treatment then she also might benefit. Her other son and daughter played an active part in supporting Joan through her illness and they had much influence in encouraging her to accept the treatment.

Interviewer: Did you discuss what was said in the consultation with your son and daughter?

Joan: Yes. They all agreed that it was the right thing to do (accepting radiotherapy).

Interviewer: What was the reason?

Joan: I suppose mainly because it was the same sort of thing as what their brother had had, and knowing how he coped and how he is now.

Does all sports. It's bound to influence you. I know he's a lot younger. Nobody ever said, but I should think that that is what they were thinking about. A couple of them said "oh that's what Philip had" (Interview 10, p6).

(Duke's C rectal cancer, widowed, retired domestic, 70)

The presence of close relatives enabled Joan to reach a mutual decision about having radiotherapy, which strengthened her confidence that this was the right course of action. Having close relatives to offer support played a significant part in the decision-making process. Even though many patients felt that they wanted to accept the offer of treatment, the presence of family members provided additional reassurance that he or she was doing the right thing, whether this meant accepting or rejecting treatment. The geographical proximity of relatives was not as central as their availability to offer emotional support and advice. If patients lived alone they might still have relatives and friends who can offer support and discuss the treatment options. Thus, the family was important for two reasons. First of all they helped patients to reach a decision. Secondly, they offered emotional support and reassurance to the patient. The patients who lived alone, and had a limited network of relatives, made treatment decisions largely with reference to their own preferences. However, patients with larger support networks often considered not only themselves but also their close relatives in any treatment decision.

Linda claimed that she wished that she was able to discuss her illness with close relatives, but she was unable to because she lived alone and had little contact with her only sister. Both her parents are dead. The lack of a support network of relatives prevented her from discussing the treatment options with anyone apart from the oncologist whose advice she subsequently followed.

Linda: I always went in on my own and everybody else seems to have half their family there. I was a bit surprised about that. I suppose it must be quite nice to bring half your family with you. But I can't think it's necessary, but everybody's different aren't they. Some people can't face things and some people can. Well, I've got to face it, I'm on my own and that's it. But sometimes you do want to talk about it. One or two people that I've got, two so called friends just turn a blind eye, they just don't want to discuss it. It's quite nice to talk about it. I'm not wanting sympathy because every other person has got cancer it appears, but it's just that feeling of getting something off your chest I suppose. It's peculiar because it bottles up a little bit inside you (Interview 19, p2).

(Duke's D colon cancer, single, property developer, 55)

Patients who lived alone, or had limited 'access' to friends and relatives, often found it more difficult to reach a decision and were consequently more likely to refuse treatment. Arthur lives

alone following the death of his wife. His decision to reject chemotherapy was largely influenced by his depression resulting from the loss of his wife that made him feel that his life was not worth living. Consequently, he did not want to prolong his life through accepting the chemotherapy.

Interviewer: What was the reason why you rejected treatment?

Arthur: I don't think I wanted any more. I was in such pain, but when I reflect back what I ought to have had is pain killers and let nature take its course.

Interviewer: Is that mainly due to your social circumstances?

Arthur: Missing my wife, pure and simple, honestly. I've had extremely bad days and not very often good days. It doesn't matter who I see, my mind always drifts away to my wife (Interview 27, p21).

(Duke's C rectal cancer, widowed, retired aerospace manager, 70)

The lack of relatives with whom to discuss the treatment options and the loss of a spouse created a set of circumstances that discouraged Arthur to take up the chemotherapy. Thus, in his case the return to a normal life was not something he felt able to do by means of undertaking further treatment. It also became evident in some (21 out of 55) oncologist-patient *interactions* that the social circumstances of patients often played a role in their decision to accept the offer of chemotherapy. Typically, those patients who lived with a spouse or could rely on support from close relatives were more likely to accept the chemotherapy, and those who lived alone without available support were more likely to question the likelihood of undertaking a long course of treatment.

For instance, the following informant clearly states that if the side effects were too severe he might not cope with the chemotherapy treatment since he lives alone and has no close relatives near by. His wife died 18 months ago.

Dr Smith: We do things according to statistics. Sixty to seventy percent of Duke's Bs survive five years. Duke's C is 30%. That's why we advise treatment. Chemo will improve your chances, with Duke's D the cancer has already spread.

Harry: I live by myself and if I have to come here every day, if I'm not going to be in good shape, then that's a paramount factor.

Later on in the consultation he continues to refer to his domestic circumstances.

Harry: What you're saying about the side effects, coping with living by myself may be a problem.

Dr Smith: We need to warn patients that these are possible side effects (Observation 6, p3).

(Duke's B colon cancer, widowed, retired mechanical engineer, 71)

Terry consequently accepted the offer of treatment. His decision to have the chemotherapy was easier because he felt he could rely on his wife. Indeed, he stated that if he agreed to have the treatment then the decision would also affect his wife who would be left with the task of caring for him. The availability of a carer seemed to play a part in Terry's decision to accept the treatment.

Dr Fenton: The question of whether preventative treatment is revisited. Chemotherapy is advantageous, and common practice for people in their sixties. Compared to other types of this sort the side effects are not so bad. The side effects involve a sore mouth, diarrhoea, nausea and general tiredness. We're not entirely sure whether benefit is clear in your case. We're involved in a study. I don't decide whether you have the treatment, a computer does. How do you feel about it?

Terry: My wife's got to bear the brunt of it (Observation 28, p2).

(Duke's B/C colon cancer, married, retired aircraft engineer, 73)

Terry's decision was made on the basis that his wife, and not only himself, was able to cope with the after effects of chemotherapy. The following dialogue was between Dr Fenton and Gerald who has terminal bowel cancer. The conversation took place mainly between the patient's daughter and Dr Fenton. Both wanted to avoid the use of chemotherapy in order to protect the patient from further suffering and to reach a decision, which would enable him to cope better during the last stages of his life. The patient played an inactive part in the consultation and it was the oncologist and the patient's daughter who referred to the patient's living circumstances when deciding about further treatment. The oncologist informed the patient that the benefit of palliative chemotherapy was uncertain in his case and that he was unlikely to live beyond a few months.

Daughter: Will he get worse? The lady he stays with will not be able to cope.

Dr Fenton: You have to get in touch with St. Peter's Hospice. You have considerable choice to keep you in the community (rather than in hospital). To think about it now is very important (to decide where to spend his last months).

Gerald: So that's it.

Dr Fenton: We should see you in a month's time to see how you're going. If you pick up we could reconsider the treatment.

Gerald: If I pick up I can have treatment?

Dr Fenton: I'm sure we can help you, and that means not making things worse for you. Is there anything you'd like to ask me at the moment?

Daughter: Dr Fenton has told us what we need to know. My biggest worry is the lady that he lives with.

Dr Fenton: That's why it's better to deal with these things in advance – it's so much better for you all (Observation 54, p1-2).

(Duke's D colon cancer, widowed, retired, 71)

The decision-making task centred on the patient's domestic situation. He lived with an elderly companion who had problems coping, and Gerald's daughter wanted to avoid causing her any further difficulties. In response, the oncologist suggested that the patient consider referral to a hospice. In the following consultation Joan also stated that because she lives by herself and has no access to personal transport, she might not be able to attend the treatment centre. However, the oncologist reassured her that hospital transport could be arranged, and this seemed to resolve the issue.

Son: When would the planning start?

Dr Fenton: In two weeks.

Joan: I live on my own. You say I would have to come here every day. That would be difficult.

Dr Fenton: You could have hospital transport, so long as you know that the bus takes its time (Observation 7, p1).

(Duke's C rectal cancer, widowed, retired domestic, 70)

The analysis in this section shows that many informants made the decision to accept chemotherapy either in discussion with close relatives or on 'behalf' of their relatives. This is largely because for patients who had family responsibilities and close relatives the chemotherapy was perceived as offering a better chance of returning to normality. For those who had limited access to social support, the practical and domestic problems associated with undergoing six months of intensive treatment were of primary consideration in decision-making.

Age and decision-making

There is an assumption in the research literature that older (cancer) patients play a more limited part in the decision-making process because they prefer to rely on the doctor's judgement, whereas younger patients are better informed and vociferous (Pierce, 1993; Thompson et al, 1993; Petrisek et al, 1997). The current study, however, has found that older patients tended to be more active in the decision-making task than many younger patients. As such, older people tended to ask more questions and actively discuss the pros and cons of treatment with their oncologist.

The analysis revealed that 'younger' informants (those under the age of 60) were more decisive about undertaking treatment than 'older' informants (those over the age of 60). This is connected to the idea that for older patients the benefit of prolonged life may not always be as important as for younger informants. Indeed, a better 'quality' of life was sometimes viewed as a more important goal. Older and younger informants in this study expressed slightly different views about the need to undertake chemotherapy, which were often related to their age as well as to their family responsibilities and their occupational roles. Indeed, for 'older' informants the knowledge that they had a more limited time scale attached to their life anyway, often influenced their decision.

A prolonged course of chemotherapy treatment was commonly perceived by older and retired informants to be a disruption to their social roles. Younger informants were more likely to view chemotherapy as a positive step towards recovery, and the disruption caused by the treatment was regarded as a temporary problem in the pursuit of long-term benefit. This is one reason why older patients found it more difficult to come to a favourable treatment decision and why the disruption of treatment was less easy to cope with. Out of 17 informants who were over 70, 14 claimed that the chemotherapy treatment signalled a possible disruption to their social roles or their quality of life. Conversely, out of 20 informants who were under 70, 15 viewed the treatment as a positive

step towards recovery and were less concerned about the disruption it might cause to their social or domestic circumstances.

Victor is 80 years of age and retired. He did not want to undergo chemotherapy, even though it was an option for him, mainly due to his age and because of the potential harmful side effects that he might experience.

Victor: The thing is that your hair comes out for a start and you feel really ill. I'd rather go on like I am at the moment...The oncologist said that it (the treatment) would take six months and even then they could not guarantee that it would not recur. And seeing I was eighty, he said (the oncologist) if I was fifty it would be another matter, seeing that I am eighty I am ten years over due anyway....Like the doctor said, if I had chemotherapy it would make me ill. I've seen people on television who had chemotherapy and they're in terrible condition (Interview 12, p22).

(Duke's C colon cancer, widowed, retired office clerk, 80)

Mark initially felt that he did not want to undergo chemotherapy after recently having two major operations. He preferred to remain as he is and avoid the treatment, which could lower his quality of life as well as stop him from doing the things he wanted to do.

Mark: I didn't feel I wanted to have it (the chemotherapy) because I was feeling so well after the operation. I felt on top of the world after the op because I wasn't in any pain which I had for a few months before hand and I felt so well. I thought I wish they've never sort of discovered chemotherapy because I felt well and I just wanted to go on, get out there and do all the things I wanted to do. I had my knee operation two years ago so I just got over two major operations and felt fine, really ready to take on the world and do everything I wanted to do and then this (Interview 30, p8).

(Duke's D colon cancer, widowed, retired bank clerk, 72)

Similarly, Joan felt that the radiotherapy treatment interfered with her daily routines.

Joan: The treatment does mess up your day because you can't do anything (Interview 10, p9).

(Duke's C rectal cancer, widowed, retired domestic, 70)

Andrew felt that the chemotherapy disrupted his desire to get back to his job, even though he is 70 years old. He finally decided against having treatment.

Interviewer: Does that kind of schedule inconvenience you?

Andrew: Well yes it is interfering with everyday life because I would like to go back to work. I don't see how I can really go back to work while I'm in treatment because my job involves a lot of driving (Interview 1, p15).

(Duke's C colon cancer, married, food inspector, 68)

Shaun wanted to get back to leading a normal life as soon as possible, and he thought that six months of chemotherapy would slow down his recovery rather than speed it up.

Shaun: We decided against chemotherapy. If you can't tell me that if there's something wrong with me then I'm not going to go through with the treatment. Because I've been progressing so well I'm not just going to think what may and may not happen. But I know how I feel and I feel that I'm doing ok and I feel that I'm getting back to normality and I'm not going to think about what may and may not happen. Nobody knows do they? (Interview 20, p18).

(Duke's C colon cancer, married, retired shop worker, has one adopted child, 73)

These informants, who were all over 65 years old, clearly felt that the long course of chemotherapy was, or could be, a disruption to the everyday social roles. Consequently, the decision to have the treatment was strongly affected by the extent to which they felt able to cope with such an interruption to their daily activities. Williams (2000) refers to Bury's (1982) concept of 'biographical disruption' as an ailment of modernity. By this he means that not everyone experiences the onset of chronic illness as a sudden and negative disruption. He claims that for people with life-long chronic illnesses or disabilities, their experience might be better described as continuous, requiring adaptation and readjustment. For other people such as haemophiliac and homosexual men with Aids, the experience of illness is not so much regarded as a disruption, but in many ways a relief or a reinforcement of one's lived identity (Rhodes and Cusick, 2000). In a similar vein, the current study reported that people who have survived into their seventies, eighties and beyond might expect to become ill due to their lower expectations of health. They may have met illness with a greater sense of acceptance, which is why some in the current study decided not to undertake a long course of taxing treatment. Thus, patients may not have the desire

to 'fight' illness at all cost. In contrast, those who do not feel that illness is inevitable might be more determined to maximise all the options available to them.

The following exchanges between oncologists and patients provide evidence to support the view that 'older' patients were more reluctant than 'younger' patients to undergo a long course of chemotherapy. This was largely because the prospect of undergoing chemotherapy, after having just recovered from major surgery, and sometimes radiotherapy, was too much to bear for many patients over the age of 65. The 'biographical disruption' resulting from treatment was too high a price to pay for many. In 41 out of the 55 observations the patients attending the consultation were aged over 65 years. Out of the 41 patients 18 expressed some level of concern about the potential impact of the chemotherapy treatment on their quality of life, lifestyle, or domestic circumstances. All of the 18 patients were over 70 years of age.

The following patients are both over 80 years of age and living alone. They were both reluctant to have any further treatment because of their advancing age, and partly because of the lack of social support.

Gary. I don't want to cause any trouble doctor. (The patient is very anxious and nervous).

Dr Fenton. Do you know why you've come here today? What do you understand?

Gary. They told me in Bath I have it in the liver. Is it very advanced?

Dr Fenton. Yes I think so. We don't have a cure.

Gary. We know, we know.

Dr Fenton. Two possibilities for the pain. We have to ask ourselves, do we give radiotherapy or chemotherapy. We cannot cure it. The sort of pain you're having wouldn't be helped with radiotherapy. Chemotherapy has side effects. It will help 30% of patients at best.

Gary. Do I keep taking the tablets?

Dr Fenton. Yes.

Gary. I don't want to be messed about doctor.

Dr Fenton. I think we ought to leave it. (The patient's wife died recently and he begins to talk about her and how he has not been able to cope without her) (Observation 34, p1-3).

(Duke's D colon cancer, widowed, retired farmer, attended the consultation with daughter, 85)

Barry also questioned the benefit of undertaking further treatment at his age.

Dr Fenton. The issue is whether to give you radiotherapy. It's like a prolonged operation. You'd feel tired, have diarrhoea, soreness, but then the side effects stop and control is maintained.

Barry. Why should that control the growth when the surgery didn't?

Dr Fenton. That's a good question...

Barry. Is it worth it at my age?

Dr Fenton. If we give you the treatment now we can cure it completely. If we wait we won't.

Barry. Is it worth me having it? How long does it take?

Dr Fenton. Five days a week for six weeks. We have a 70% chance of curing it.

Barry. I'll leave it in your hands then. If you think it's worth it in your judgement then I'll leave it to you. (Observation 48, p1-2).

(Duke's C rectal cancer, single, lives alone, retired 'manual' worker, 80).

Barry wanted to know if the treatment was worth pursuing at his age. The oncologist reassured him that there was a good chance of cure, which persuaded the patient to follow the doctor's advice. It was evident though, that Barry seemed to be reticent about the benefit of having prolonged treatment given that he was 80 years old. Dennis who is 75 years old has already had an operation for bowel cancer where he was fitted with a colostomy bag that has been causing him practical problems. He also had a course of radiotherapy. Regarding the decision to undertake six months of chemotherapy he expressed serious reservations during the consultation and finally declined the treatment. As with the previous patient, Dennis felt that at his age another six months of treatment would cause too much disruption to his quality of life having already had a course of radiotherapy.

Dr Fenton: The radiotherapy is recommended but the chemotherapy we are not sure, so we're not happy that you should have it outside of the study. The radiotherapy and the chemotherapy do run together.

Dennis: It takes a bit of time to think about. I was expecting that I would only have radiotherapy.

Dr Fenton: We would like you to go in the study. It's nationwide.

Wife: How can you tell how successful the chemotherapy is?

Dr Fenton: We do statistical analyses to determine. I would rather you went in the study.

Dennis: What kind of benefit would I have with the chemotherapy?

Dr Fenton: It reduces the chances of the cancer coming back.

Dennis: At the hospital everything was fine and all of a sudden they said a few weeks later about the lymph node that was involved. I was surprised. When I went out of hospital I was under the impression that it was just radiotherapy, and the chemotherapy was not being considered. Mr Smith (surgeon) said that the liver and lungs were not involved. I said how can you tell?

Dr Fenton: We would have to magnify the picture hundreds of times to get the whole picture.

Dennis: How long daily does the treatment take?

Dr Fenton: Twenty to thirty minutes. It's quick.

Dennis: I am not worried about this, it's the other aspects of treatment I'm worried about (side effects).

Dr Fenton: I think you should consider seriously about going into the study.

Dennis: Why?

Dr Fenton: Because you're fit. We don't know which treatment is beneficial. Research is part of my job (Observation 41, p1-3).

(Duke's C rectal cancer, married, retired, 75)

Dennis expected to be offered radiotherapy alone, which lasts several weeks rather than months. However, the oncologist was pressuring the patient to accept the offer of chemotherapy and Dennis found this confusing. The potential disruption of chemotherapy became a serious issue for Dennis, which he was unable to resolve immediately. He left the consultation without making a decision, but a week later he phoned to inform the doctors that he had decided against any chemotherapy. Contrary to the belief that 'older' cancer patients play a limited role in the treatment decision-making process, this analysis has indicated that 'older' patients were more likely to engage in a deliberation with the oncologist than 'younger' patients, who often did not feel that refusing treatment was a real option. Older patients often have to consider the impact of prolonged chemotherapy on their quality of life as well as their social circumstances.

'Younger' informants frequently believed that chemotherapy would be a disruption to their working lives, although their concern was overshadowed by the need to get well as quickly as possible. The interference of the treatment course was often played down and the benefits were emphasised. They often felt more optimistic about the benefits of chemotherapy and the chance that this would give them to get back to 'normality'. Consequently, they were much more likely to accept the offer of chemotherapy. For instance, Vincent felt that the side effects were a small price to pay in return for a better chance of survival.

Vincent: I had a choice. I thought ok the treatment is experimental, can't guarantee nothing but it's better than nothing. Better than sitting and worrying whether I should've had it. I'm telling myself now that I'm going to go right through the six months. I'm not going to back out. I might feel bad for a week or whatever it is, I've got to go through with it (Interview 32, p6).

(Duke's C colon cancer, married, unemployed, has one son, 56)

The side effects did not dissuade Vincent from having chemotherapy. Hillary also wanted the chemotherapy out of necessity rather than choice. The side effects did not prevent her from accepting the treatment.

Hillary: But you know, I mean I'm prepared to have the chemo even if it makes me ill. It's a case of having to isn't it really (Interview 22, p23).

(Duke's C rectal cancer, married, no children, part-time domestic cleaner, 63)

Dianne claimed that she made a quick decision to accept the chemotherapy, as she did not feel that she had a 'realistic' choice to refuse the option. The potential disruption of the prolonged treatment course did not discourage her from accepting it.

Dianne: We didn't go away to think about it (her and her husband). The decision was made there and then because it seemed like Hobson's choice (Interview 26, p14).

(Duke's C rectal cancer, married, accounts clerk, 57)

Yvonne also claimed that the side effects would not prevent her from having the chemotherapy since she saw it as her only chance of a longer life.

Yvonne: If you're the person who has cancer you're going to cling onto anything at that stage. If it's going to prolong your life a couple of months you'll put up with the side effects. If the doctors haven't gone through cancer themselves then they can't know what that person's going through. I think it's only the people who have gone through it can appreciate it. That person would put up with anything (Interview 7, p12).

(Duke's D colon cancer, married, social worker, 37)

Deciding on what constitutes 'old' is problematic because chronological age is often arbitrary in the context of life threatening illnesses. For some people 'older' age does not present any restrictions on daily living, whereas for others age imposes physical limitations that can influence their decisions and affect the value they attach to their 'quality of life'. The issue of whether to accept or refuse oncological treatment was often coloured by an individual's physical health. In the current analysis, it was evident that people who were over seventy tended to approach the issue of side effects, and the social disruption caused by prolonged toxic treatment, with greater caution and concern than those who were in their forties, fifties, and sixties. Certainly, for some people who were in their sixties the issue of side effects and treatment duration also presented a problem. On the whole, the importance that patients attached to their quality of life during the decision-making process was age related.

Gender and decision-making

Responses to side effects

Most studies to date, which have addressed the issue of gender and decision-making in cancer treatment, have focused on women and their decisions regarding breast cancer treatment. For this reason, gender differences have not been explored adequately, and the views of men have been largely absent in past research on cancer. This study has attempted to explore the issue of gender in the decision-making behaviour of bowel cancer patients. Relatively few differences were identified between men and women, probably because what seemed to be most central to their concerns was the issue of survival. Thus, the illness experiences of men and women were similar during the initial stages of their illness and its treatment. In many cases the issue of gender did not play a central role in their decision-making preferences or behaviour.

The issue of treatment side effects, however, was an issue where gender differences were evident. Previous research on breast cancer has shown that women's choice of mastectomy versus lumpectomy with radiation therapy is not influenced by factors relating to body image or surgical procedure (Fallowfield et al, 1990). Women make treatment choices according to the procedure that is thought to provide the best chance of cure and prevent recurrence. Chemotherapy for bowel (or breast) cancer raises specific problems relating to side effects and the length of treatment, which do not apply to surgery. One of the issues that concerned more women than men during the decision-making process was whether the chemotherapy was likely to cause significant social or emotional 'disruption' to their lives. For instance, the fear of hair loss, loose bowel movement, diarrhoea, and nausea, were frequently cited by women as a concern during the decision-making process. Some male patients also expressed concerns about side effects, but they viewed them generally as a 'means to an end'. Men frequently described how they would attempt to manage and control their side effects, whereas women were more conscious of their impact on bodily and social function. Thus, for women the likelihood of experiencing adverse side effects was a more salient issue, but it was not always the determining factor in their treatment decisions. Women frequently avoided discussing these concerns with the oncologist at their first consultation. Out of 13 female interview informants, 10 expressed concern about side effects and their likely impact on their social and physical functioning, 7 finally refused (or stopped) treatment where the issue of adverse side effects was a central issue. Out of 24 men, only 3 expressed concern specifically about side effects. None of the male patients refused the offer of treatment on the grounds that they may not cope with the side effects.

Eileen: The only thing I worry about is my bowel being loose. I hate to be embarrassed...I wouldn't worry about the ulcers if the loosening of your bowel was corrected. It's an embarrassing side of it. It's not nasty nasty for you but because you don't get pain, you're just loose, but the thing with this is it's very embarrassing. If you were anywhere and that happened, you can't control it. You'd be inclined to stay in doors, you know, not go too far (Interview 24, p12).

(Duke's C colon cancer, retired school caterer, widowed, has one daughter, 61)

For Eileen, the main concern was the extent to which her loose motions would cause her any embarrassment and whether this would prevent her from carrying out her everyday activities. The issue of side effects was important for women, although the degree to which it influenced their treatment decision is not clear. Generally, women expressed some concern about bowel movement or hair loss. However, few women actually stated that the fear of side effects led them to decline the treatment.

Linda: He answered all the questions I wanted to know. I suppose one big problem, my hair, would I lose my hair? That was one of the main problems. He said only five percent of people lose their hair so I was unfortunate if I lose it with this particular chemo (Interview 19, p23).

(Duke's C colon cancer, single – lives alone, property developer, 55)

Joan: My son and daughter came with me and we did ask about the side effects. I was a bit worried about losing my hair. He said I wouldn't lose my hair. The side effects would only be in the part of the body that they were directing the rays to, which would probably be a bit of diarrhoea, I'd feel very tired and not a lot else. I think it was the side effects I was more worried about than the treatment itself. It did worry me about deciding to have the treatment (Interview 10, p6).

(Duke's C rectal cancer, widowed, retired domestic, 70)

Linda and Joan both felt anxious about the possibility of hair loss, but the oncologist reassured them that this was unlikely. The oncologist often provided reassurance that patients would be closely monitored and that the side effects would be controlled with medication. Hillary, on the other hand, was afraid that she would experience nausea as a result of the chemotherapy.

Hillary: He (Dr Fenton) said did I hear anything about it (the side effects), and my husband chipped in there and said "doctor, she's so afraid of being sick", and I am. I'm terrible. I'm awful when I'm sick, always have been. I can't change. People say ooh you'll be sick a lot, and I think oh how am I going to cope with it? But I mean I might sail through it, who's to say. (Interview 22, p23).

(Duke's C rectal cancer, married, no children, part-time domestic cleaner, 63)

She continues:

Hillary: The thing is you hear so many stories of what other people tell you. If it wasn't for my daughter and sister in law (who encouraged her to accept chemotherapy) I would've turned around and gone home. It was awful. You hear stories about losing your hair and I thought I just can't handle this (Interview 22, p23).

(Duke's C rectal cancer, married, no children, part-time domestic cleaner, 63)

Lillian was aware that women and older patients tend to suffer with worse side effects due to chemotherapy. Although this was not a major concern for her, she was somewhat anxious about the combined impact of all the side effects.

Lillian: The only thing I had been told was I'd be sick, have diarrhoea, a sore mouth, which are all unpleasant things. As he explained for some reason or another, it seems to affect women more than men, the side effects. It seems to affect them more the older they get, up to the age of seventy five (Interview 36, p12).

(Duke's C colon cancer, married, retired, 70)

Most women of all ages expressed some concern about the potential impact of the side effects on body image, the experience of pain, and social stigma. The breast cancer patients in Fallowfield et al's (1990) study, made surgical treatment choices on the basis of the most likely procedure that would extend survival and prevent recurrence. They did not make treatment choices on the basis of the surgical option that would have the lowest impact on body image and psychological morbidity. Chemotherapy is administered as a second-line treatment, and consequently might be regarded by some patients as 'optional'. In contrast, surgery is usually a routine first-line treatment where there is often limited patient choice. Some patients might consider chemotherapy

to be less important than surgery in its overall objective of eradicating the cancer, and therefore, the issue of side effects might play a more central role in the decision-making process. Although the issue of treatment side effects may not have always affected the final treatment decision, it was clearly an area of concern for female bowel cancer patients. The research literature, which has mostly reported women's experiences of toxic side effects resulting from chemotherapy for breast cancer, strongly indicates that patients will tolerate adverse side effects for minimal survival benefit (Mcquellon, 1995; Yellen and Cella, 1995). However, these studies do not consider the attitudes of men, or of patients with different cancer diagnoses, including colorectal cancer. In fact, in the current analysis, male patients tended to express similar attitudes as those found for women with breast cancer regarding side effects. Men were more prepared to tolerate high levels of inconvenience and toxicity in exchange for the possibility of cure. In contrast, the female bowel cancer patients attached more significance to the toxic side effects and their impact on negative body image.

Men perceived the toxic side effects as a price that they were prepared to pay for successfully completing their treatment course. Their need to tolerate the side effects was an expression of their desire to maximise their options in order to return to 'normality' as quickly as possible. Whereas women were concerned about the impact of toxicity on their body image and the risk of social stigma, men tended to accept the side effects, which they perceived as a necessary means to an end. However, that is not to say that men did not consider the potential disruption that a prolonged course of chemotherapy might inflict on their lives, health, and body image. It is simply that men were more optimistic, and sometimes even dismissive of the side effects.

Interviewer: Do you have confidence in the actual treatment?

Patrick: The nurse explained all this to me. She gave me a whole list of what to expect, and she said it all depends on the individual. Some individuals get along alright, and another person unfortunately gets all of them (side effects) and has to have a terrible time of it. I think people are prepared for a bit. I take it that if you get any injections you're bound to get a side effect of some description from it. Drugs going through each day for a week, you're bound to upset the system somewhere (Interview 31, p4).

(Duke's D colon cancer, married, retired office worker, 74)

Patrick was philosophical about the potential impact of the side effects on his body, and was prepared for the worst. Henry also felt very positive about the treatment course and did not consider the side effects to be a central concern in his decision to have the treatment.

Henry: I went into it (the chemotherapy) with an open mind, and as far as I'm concerned I'm getting good treatment. As I understand it the trial is to see whether you need a small dose or a large dose. So I'm getting it, so what's the problem? It (the treatment) doesn't bother me (Interview 6, p11).

(Duke's C colon cancer, widowed, one daughter, retired bank worker, 74)

Terence also felt highly positive about his ability to cope with side effects. He claimed that his colostomy bag was in fact an advantage, because it helped to contain the diarrhoea.

Terence: Generally speaking people think that having a colostomy bag is something they wouldn't like to have, but when you get used to it, it's no different really from coming out of the natural orifice, it's just going into a bag. If you get severe diarrhoea as a result of the side effects, it's a positive advantage actually. You haven't got that deadly fear that you'll be sitting in a restaurant and all of a sudden rollocks. It just means you have to empty the bag four times a day instead of one. It's a positive advantage being an osteovite (Interview 29, p14).

(Duke's C rectal cancer, married, retired Police Officer, 60)

Graham: As I said, I have a very good friend of mine who had breast cancer a couple of years ago. Life's pretty bloody hard for her and I tried to support her. I was telling her I was feeling sorry for myself (after the first meeting with the oncologist), and she said to me "I don't know what you're bloody going on about, you're going to have about ten days of discomfort on six occasions. Just thank the stars you're not a bloody woman. You'd have a period every month for about forty years" she said. You either can cope with the side effects or you can't. If you can't cope with it you got to stop having it, if you can cope with it you got to get on with it (Interview 17, p8).

(Duke's B/C colon cancer, married, retired Fire Brigade Chief, 63)

Patrick: In fairness to your answer, I'm quite confident because I say to myself well I've got to beat it or I've got to win, and there are people who are trying to help me with this medical side of it, so I've got to do my side of it (Interview 31, p7).

(Duke's D colon cancer, married, retired office worker, 74).

Patrick felt obliged to tolerate the side effects and do his best to overcome them since the oncologists were doing their best to help him and he wanted to do his best. Thus, he felt that it was his duty to enter into treatment in a positive frame of mind. Graham was also philosophical about the issue of treatment side effects.

Derek: You mustn't read too much into the side effects because otherwise you might not take the treatment (Interview 23, p17).

Robin: I questioned the doctor quite a lot about the after effects and side effects, and of course that's different in every case, no hard and fast rule on side effects, but they can be quite nasty. I understood that and that's a risk you take (Interview 13, p20).

(Duke's C rectal cancer, married, retired office worker, 75)

Men did not relate specific side effects to bodily and social functioning. The likely influence of mouth ulcers, diarrhoea, hair loss, and nausea on physical and social functioning was treated with a greater sense of acceptance. However, women often viewed the side effects in terms of their potential social disruption and their impact on physical functioning and body image. Thus, the risk of hair loss, or the inconvenience and embarrassment that could result from diarrhoea, were important concerns for women. Indeed, some even threatened to reject the treatment on the basis that they may not cope with the toxicity. However, this could have been confounded by the fact that more women lived alone, and therefore, they had to consider the availability of social support from friends and relatives during the treatment course.

The role of emotions in decision-making

The idea that patients act as health care consumers, who can make independent treatment decisions on the basis of the information given to them, is not supported by the current study. The experience of life threatening illness often interferes with the patient's ability to make calculated, rational decisions since 'emotion' often plays an important role in the decision-making process. Lupton (1996) suggests that although scientific information can provide patients with one way of approaching the decision-making task, the emotions that accompany chronic illness can also play a central part in the decision-making process.

Trust and decision-making

The analysis has demonstrated the central importance of the oncologist's treatment recommendation and the need for the clinician to be honest in enabling the patient to reach an acceptable decision. Connected to this is the finding that patients express a high level of trust in their oncologist. This section explores the concept of trust, the extent to which it was important in helping patients reach an acceptable decision, and the strategies informants used to maintain their trust in the oncologist. Most informants were aged over 60 and may have been less inclined to rely only on their own judgement during the decision-making task. However, 'younger' informants also expressed a similar degree of trust in the oncologist as their 'older' counterparts. Thus, the desire to invest trust in the specialist was probably determined more by the nature of the condition and the perception that cancer specialists know what is 'best' for their patients, rather than the age of the informants. At the time of the first consultation with the oncologist most patients had a vested interest in trusting the specialist because they only had a limited understanding of their disease and the treatment options available to them. Consequently, they often had little choice but to trust the oncologist's recommendation.

The analysis in this section also demonstrates how trust in the oncologist helped patients to adapt to their new identity as cancer patients by enabling them to manage other emotions such as fear, uncertainty, anxiety, and self blame, which are often typical responses to a cancer diagnosis. Trusting the clinician allowed patients to lift at least some of the emotional burden and it was a first step in managing and coping with their illness. Although patients did not often talk explicitly about fear, this was an emotion evident behind their views on treatment decisions and the trust they had in their oncologist. It seemed that patients' fears about cancer and possible or inevitable

death, motivated them to trust their oncologist completely. In turn, their trust in the oncologist helped them to manage their fears and other related emotions.

The following interview quotations are typical of the reasons informants expressed about the need to trust the cancer specialist. Most responses suggested that the informants did not feel confident about making a treatment decision without the oncologist's input and therefore felt compelled to place a high degree of trust in the specialist. Out of 37 informants, 27 expressed a high level of trust in their oncologist. All informants stated that they had at least some trust in their specialist, and none stated that they distrusted their doctor. Out of 37 informants, 26 claimed that their trust in the oncologist enabled them to follow his/her treatment recommendation.

Linda: If Dr Fenton told me now anything, I mean if he really did tell me that I sort of had to eat a bag of soot a day I would try it to the best of my ability. Yeah because I just feel that they knew best. I put my trust in him and nobody else (Interview 19, p13).

(Duke's C colon cancer, single, property developer, 55)

Linda claimed that she would be prepared to try any treatment that the oncologist recommended to her if it would increase her chances of survival. Similarly, Terence had implicit faith in both his bowel surgeon and the oncologist, which made his decision to have chemotherapy treatment fairly straightforward. He also claimed that the trust he had in the oncologist removed the need for him to discuss the treatment options with his close relatives.

Terence: Right from the start I trusted implicitly everything they (the oncologist and the bowel surgeon) told me and took the advice and followed to the letter everything that they told me to do.

Interviewer: Did you talk over the decision with your family?

Terence: No. I suppose we did talk about it but it never took the form of a discussion about you know, there are two alternatives, which one are we going to go for. Both of us (him and his wife) took it as self evident from the start that if these people are far cleverer than either of us are ever going to be on the subject, if they recommend doing it, we do it. You got to trust these people because they are people who have devoted their lives to helping other people (Interview 29, p14).

(Duke's C rectal cancer, married, retired Police Officer, 60)

Terence clearly did not feel that he had the knowledge to question the treatment recommendation of his oncologist, which in turn removed the need for him to take part in any form of decision-making. In a way his trust in the oncologist's judgement acted as a 'barrier' to the pursuit of an alternative treatment plan. Graham similarly felt that it was in his interest to trust the oncologist since distrust would not help in his recovery. Also, he implied that trusting the clinician's clinical judgement was a way of displacing negative emotion which might otherwise be 'released'. Indeed, Graham had implicit faith in the oncologist, which was not greatly affected by the disclosure of adequate information to the patient. The central component of the doctor-patient relationship was the ability for the patient to trust the doctor's advice.

Interviewer: Do you think that the more information patients are given the more likely they are to trust the doctor?

Graham: I applaud the theory, and I'm certain that in certain cases that makes it so. But looking at the other side of the coin, why do I go to see Dr Fenton rather than any other oncologist? Basically because they're there. If I say to Dr Fenton "well I don't really like what you're telling me, can I have a second opinion?" You sort of think well where does that leave me? Supposing I said "look you got it all bloody wrong, you told me so many stories I don't know where I am, I don't want any bloody treatment" So where's that going to take me? I go about my normal way of life and every time I have a headache "oh Jesus have I got this again?" (Interview 17, p17).

(Duke's B/C colon cancer, married, retired fire brigade chief, 63)

Arthur also felt that most people have an implicit trust in doctors, and when they present a logical argument to the patient it is difficult not to follow their advice. Thus, for Arthur, the doctor's ability to provide a rational explanation about the pros and cons of treatment reinforced his faith that he was receiving the best care.

Interviewer: Did you feel you had a part in making the decision about the treatment?

Arthur: No. How could I influence something like that? He's the specialist not me. He told me something which appeared totally logical and I went along with it, it's as simple as that. I'd trust somebody with my car but I wouldn't trust a car mechanic with my body (Interview 27, p26).

(Duke's C rectal cancer, widowed, retired aerospace manager, 70)

This theme has demonstrated that most informants, irrespective of their age, invested a high level of trust in their oncologist, which often made the task of deciding much simpler. Patients often felt able to accept the advice or recommendation of the oncologist uncritically. Indeed, in some cases the faith that patients placed in their oncologist even removed the need to discuss in great depth the treatment decision with their relatives. Following the doctor's advice was in itself a means of repressing their fears, and of preserving a sense of hope that the best was being done to treat the disease. (The issues of hope and fear will be returned to in greater detail in a subsequent section).

Maintenance of trust

The analysis revealed that bowel cancer patients held firm views about the ways that trust in the cancer specialist needed to be maintained. There were certain rules which informants felt needed to be adhered to by the doctor for their trust to be secured. Thus, trust was something that had to be sustained or negotiated between the doctor and the patient since it often rested on the oncologist's ability to satisfy the patient's expectations of the doctor's role. The maintenance of trust was frequently established through the expectation that the doctor had superior knowledge to the patient and made decisions as honestly as possible with the patient. Trust was, therefore, established through the recognition that the doctor would largely adhere to the 'paternalistic' role. In other words, that he or she would take a lead in the decision-making task. It is also believed that trust needs to be secured through mutual disclosure and open communication (Lupton 1996). It was evident from the analysis that trust was an essential ingredient within the doctor-patient relationship, although its boundaries needed to be frequently negotiated and maintained.

Out of 37 informants, 30 stated that trust had to be maintained, and was open to re-evaluation and assessment by the patient. Out of 37 informants, 31 claimed that trust was largely dependent on strong interpersonal skills of the doctor, such as the ability to listen, communicate well, and offer empathy.

While the consumerist approach is insistent upon the need for members of the lay public to approach the medical encounter in a 'rational', calculating and dispassionate manner, the experience of illness, physical dependency and vulnerability goes beyond conscious rationality to a situation of semi-conscious or unconscious needs, desires and emotional states (Lupton, 1996: p.166).

One of the most important emotions that were expressed by patients in the current study was trust. The following interview quotes demonstrate the conditions that patients identified for the successful maintenance of trust between the doctor and the patient.

Interviewer: Do you feel that if you weren't given all the information that you would lose some confidence in the doctors?

David: I wanted to know what was going on. I didn't want to be kept in the dark. There's nothing worse than being kept in the dark and then not realising you are kept in the dark, and then realising you had been kept in the dark. That sort of shatters your confidence (Interview 35, p9).

(Duke's D colon cancer, married local government officer, 64)

Interviewer: Would you say that by acquiring more information your trust in the oncologist was strengthened?

Harold: Well of course it was. If they're honest with you and put the cards on the table then you're bound to have more trust. It strengthens your belief in them.

Interviewer: Some people have told me that they trust the doctor no matter what, whether they disclose all the information or not.

Harold: No, no. I don't believe in blind faith (Interview 28, p5).

(Duke's C colon cancer, widowed, retired insurance broker, 75)

For David and Harold, full and honest disclosure of all the facts was vital to the degree to which they were able to trust their clinician. Frank, however, expected his oncologist to appear confident and knowledgeable about his job. By showing that he knew what he was doing, the oncologist strengthened Frank's confidence in his skill as a cancer specialist.

Interviewer: What do you expect of an oncologist?

Frank: Confidence. Quiet confidence. No rush, no televised emergency ward where people are rushing about like headless chickens. That's not medicine is it? How can you instil confidence in the patient if you gonna get up and run around shouting your head off. You want a quiet, confident man who knows what he's doing, even if you're going under. "Right" (claps hand). "Get on with the job". Quiet confidence, that's

all you want. There's plenty of that in the chemotherapy ward. Plenty of it (Interview 21, p11).

(Duke's C rectal cancer, married, retired salesman, 65)

For Eileen, mutual openness was a prerequisite for the maintenance of trust. The need for both parties to feel that they can communicate freely without any inhibitions or restrictions was vital to the maintenance of trust.

Eileen: I think he's so convincing. I didn't want to go in, but then as soon as I came in to see the doctor I came out feeling fine. "Chat, chat, chat" wasn't it (to daughter). Gives you some confidence....I think when people don't want to be told the truth, like my GP told me, it's so awkward. They know actually what's wrong with the patient but they can't tell them and they go round in circles. They can sit there and think "well, this patient is a colon, what the hell am I going to say to her or him". I think you get more confidence in the doctor and I think they get more confidence in you because they can sit and they can tell you (Interview 24, p12).

(Duke's C colon cancer, retired school caterer, widowed, 61)

Similarly, Terry felt that an openness and honesty from the clinician is fundamental to the maintenance of trust between the doctor and the patient. He also claimed that he would have complete trust in the doctor unless s/he abused that trust.

Interviewer: What types of things enforce trust in your specialist?

Terry: A frankness, an openness on his part. As far as the specialist is concerned I don't think anybody could get any better treatment. His general attitude towards me, his handling of me and my wife, he's made us at ease. Never once have I felt let down by him. I go there trusting these people and until they break that trust or do things for me to lose my trust then I will keep on trusting.

(Duke's B/C colon cancer, married, retired aircraft engineer, 73)

Terry valued the inter-personal elements of the doctor-patient relationship, such as the feeling that he was being told the truth and made to feel comfortable by the specialist. Terry gave an example of why he was losing confidence in his heart specialist, who did not view his condition with much urgency, and failed to arrange an appointment with him despite promising to do so.

Terry: I have said to my heart specialist, "is it possible to have anything done to alleviate my condition?" But he gave me no prognosis. And yet I still trust him enough to go back. I'm getting to the stage now that if I don't see him shortly within the next two or three months I'll say I've lost faith in him and I'll want to see another heart specialist. Because as far as I'm concerned, I'm a human being and I treat him with respect, and I expect him to treat me with respect. And because I'm seventy three I mustn't be thrown on the scrap heap (Interview 33, p18).

(Duke's B/C colon cancer, married, retired aircraft engineer, 73)

What was important for Terry was the perception that the clinician would do all he or she could to help him recover from his illness. Terry felt that the heart specialist was not fulfilling his duty as a doctor by failing to arrange a new appointment and by avoiding him. Consequently, Terry started to lose faith in the surgeon. Other informants felt that their confidence in the oncologist was strengthened by the way they were included in the decision-making process.

Lillian: Although the oncologist can't say a hundred percent that I will be cured, what he did do is, he inspired the confidence in the fact that the treatment is there and everybody is behind you getting it done. You get the feeling you're not on your own. There is a system and there is a team, and it's all working for you. It's all part of the picture.

Lillian felt that her confidence in the doctor's judgement was greatly increased by the way the system, and not just the leading clinician, was geared towards helping the patient achieve full recovery. Her decision to accept the doctor's treatment recommendation was a first step in strengthening her faith in the medical 'system'.

Lillian: It's no good having a patient who's uncomfortable, suspicious and "why are they doing it?" I like the way they bring you into everything. They don't do anything without telling you why they're doing it...If you don't have the trust you wouldn't go there. Confidence is what's built up over a period of time. You get to know the person and the person gets to know you (Interview 36, p8).

(Duke's C colon cancer, married, retired, 70).

Similarly, Dianne felt confident in the way the oncologist reassured her that help and advice was available round the clock if she needed it. It was the interpersonal aspects of the doctor-patient relationship, which instilled a sense of trust in the oncologist. For example, the reassurance that

direct access to medical advice was important, so too was the perception that doctors had time for the patient.

Dianne: He took the trouble to explain things and he was there if you needed him. If you had anything worrying you he said get in touch, and he was there, he was there for me. And he did his best to explain it, he sat on the side of the bed and talking in layman's terms, in language I could understand, and he seemed to find the time to do it (Interview 26, p9).

(Duke's C rectal cancer, married, accounts clerk, 57)

The themes in this section define some of the ways in which the trusting relationship between the cancer specialist and the patient was maintained. The responses suggest that interpersonal skills are highly valued and help to strengthen the bond between the patient and the doctor. For instance, the perception that the clinician is being honest with the patient, is able to listen and keeps the patient well informed and made to feel at ease were central to the maintenance of trust. Many of these qualities such as the ability to make the patient feel at ease, respected and cared for, are not always successfully taught in medical school. Consequently, such qualities are often dependent on the personality of the clinician.

The idea that trust is something that must be maintained implies that it is also an emotion that can easily be undermined or damaged. This suggests that trust needs to be 'earned' by the doctor and cannot be assumed to exist independently of the therapeutic relationship between the doctor and the patient. Similarly, the analysis indicates that the doctor-patient relationship is in a constant state of 'flux', whereby ongoing contact with the clinician often leads to the identification of new issues and problems for discussion. This may involve a discussion of the next management plan for a patient who has gone into remission or suffered a relapse. Living with cancer often involves adapting to, and coping with, changes in disease progression. This will inevitably raise new questions regarding patient management. During the course of illness and treatment, these questions are negotiated with the doctor and simultaneously the issue of trust is subject to re-evaluation by the patient. The themes in this section show that although patients invest a great deal of trust in their clinician, they also possess clear views of how this trust could be damaged on the one hand, and strengthened on the other. Indeed, it is evident that throughout the treatment course, the trusting bond between the doctor and the patient is constantly under review.

Managing fear and maintaining hope

There is a plethora of literature pertaining to the consumerist doctrine that patients should be given all the available information so that they can make rational and informed choices regarding their treatment. However, advocates of consumerism often dismiss the fact that patients may not always want to know everything about their illness. Informants in this study often claimed that they did not want to be told everything about their illness as too much information could lead to confusion. Also, it was felt that the 'wrong' type of information could affect the extent to which they were able to feel optimistic and hopeful. In other words, their fear would get the better of them. The need to maintain trust in the doctor is closely linked with the desire to suppress fear and feel hopeful about the future. Just as patients wanted to avoid the stress of having to carry the emotional burden of a cancer diagnosis, similarly the avoidance of certain types of information helped them to ease that burden further still. Generally, some informants claimed that they wanted to avoid prognostic information or information, which would threaten their ability to secure some hope for a full recovery.

'Biographical threat'

The notion of a 'biographical disruption' is used in medical sociology to describe how illness leads a person to redefine their role and undergo a period of adjustment and adaptation (Bury 1982). The idea of an illness which causes disruption to a person's life, implies that the individual must have already accepted or recognised their diagnosis (at least to some extent) for the disruption to have taken effect. However, the notion of a 'biographical threat' could be used to imply that an individual may not have completely accepted their diagnosis as it merely poses a *threat of disruption* rather than an 'actual' *disruption* to their identity. He or she may prefer to cope with their illness through the denial of certain information in order to manage the threat that it presents to their sense of wellbeing. For certain informants in the current study, the cancer diagnosis presented a threat as well as an 'actual' disruption to their self-identity. Some patients avoided certain types of information so that they would not have to confront the diagnosis of cancer in an explicit way. This helped them to maintain a sense of hope about their illness and its future outcome. Many patients perceived their condition not just as a social and a physical disruption to them in the *present*, but also as a *future* threat to their survival.

Out of 37 informants, 20 claimed they actively avoided prognostic information or details about the likely course of their disease. The following responses are typical of the entire sample of interviewees regarding this theme. Ann wanted to avoid any prognostic information in case it revealed 'bad' news for her.

Ann: What I don't know, to answer your question, is whether I want to ask if it's spread what could I expect in the way of symptoms. I don't want to ask that because I've got a very vivid imagination and I will produce them (the symptoms). If the doctor says "you'll get a lump". I don't really want to know, I just want to get better. All I want to hear from people is "you've done extremely well. There's now no sign of any cancer. Go and sin no more" That's what I really want to hear.

Interviewer: Would you like to have had more time in the consultation to ask about what happens after treatment?

Ann: That was an important question which I didn't ask, I think probably because I didn't want to know the answer.

Husband: Yeah, there would have been nothing to prevent me from saying "if you (his wife) don't want to go into this (prognosis) go outside, I want to speak to Dr so and so" (Interview 18, p9).

(Duke's C recto-sigmoid cancer, married, complementary therapist, 66)

Ann wanted to avoid any negative information that could pose a threat to her sense of wellbeing and sense of hope about the future. Similarly, Yvonne did not want to hear her prognosis as she anticipated that it was likely to be 'negative'. She describes her reactions to the initial consultation that she had with the oncologist.

Interviewer: Going back to your first consultation with Dr Fenton. After that you say you had a chat with the nurse?

Yvonne: She asked me what Dr Fenton had actually said, to go over what he said. But basically I mean at that point you feel, at that point I really didn't want to ask anything, all I wanted to do is get out. You know, at that point for me I didn't want to ask anything you know. Sort of like what he told me it's not what I expected to hear basically (Interview 7, p12).

(Duke's D colon cancer, married, social worker, 37)

Yvonne did not want to ask any questions about her illness and treatment, following her consultation with the oncologist in order to avoid further stress and worry. Avoidance was her

way of coping with the uncertain nature of her disease. Similarly, Brenda did not ask the oncologist how long she had left to live because she did not want to know the answer.

Brenda: I don't really want to know any more about what's going on inside me. As long as I'm feeling well and I'm being treated well, I don't really want to go into all the nitty gritty... We've already said, the one question neither of us asked Dr Fenton which most people immediately ask is "how long". We didn't ask him. I don't think it's fair to ask that question. But we wouldn't want to know anyway (Interview 8, p19).

(Duke's D colon cancer, married, retired domiciliary worker, 66)

Brenda wanted to avoid any information relating to her disease status since what was important to her was that she felt well in herself. Moreover, she made a conscious decision to avoid asking the oncologist how long she had to live, as she did not want to know the answer. This could be interpreted as a way by which Barbara attempted to displace the threat posed by her diagnosis. Linda and Ann also wanted to avoid prognostic information in the fear that they would receive bad news.

Interviewer: Have you sought any other types of information?

Linda: Only from Dr Fenton. One friend bought me some books, I haven't even opened a page. No I know basically what it is and what's happening. Ignorance is almost better. I mean I'm not stupid, I'm not that ignorant, but sometimes you start delving into things, you can make yourself a lot worse (Interview 19, p3).

(Duke's C colon cancer, single, property developer, 55)

Linda did not want to know too much about her survival chances because she felt that would cause additional distress and worry.

Interviewer: Did you ask the doctor what would happen after chemotherapy?

Terry: No I didn't ask because I wake up every morning and thank the Lord that I'm alive. I don't look for tomorrow. No way anyone, no matter who he is, is going to tell you how long you've got to live. Your maker decides when he wants you home and that's it, he calls you up and that's it, you go. Don't let any doctor fool you and tell you you've got four or five years (Interview 33, p16).

(Duke's B/C colon cancer, married, retired aircraft engineer, 73)

Terry did not want to know how long he had left to live as he coped better with the uncertainty. Even though men seemed to be reticent about asking the oncologist to disclose prognostic information, they were more likely to ask about their survival chances. Terry was one of the exceptions. Women, on the other hand, seemed to cope better by not knowing their survival odds.

Interviewer: Did the oncologist explain to you the purpose of the chemotherapy?

Wife: Yes she did really because she explained it better. She didn't tell us what the ratio was, I gather it's fairly high from what she said (she means low odds). She said you don't really want me to tell you.

James: Although I asked her, I didn't really want to know the answer (Interview 34, p9).

(Duke's C rectal cancer, widowed, unemployed, 55)

Tim: The problem is if you asked a lot of questions, what you are likely to get is a load of bad news (Interview 5, p21).

(Duke's D colon cancer, married, pharmacist, 58)

More women than men avoided prognostic information as a way of maintaining a sense of hope. Men were more likely to ask the difficult questions about survival. However, in most cases male patients only asked the question "how long" when it was evident to them that they were terminally ill, and then they felt compelled to ask the clinician.

Biographical 'reinforcement'

Although some patients claimed that they wanted to avoid prognostic information or 'bad news', the observational data clearly shows that some patients asked the oncologist at the first consultation to provide them with a prognosis or an indication of time-scale. All of these patients had terminal illness. However, most informants seemed to cope with their diagnosis by being more selective with the information that they received from the oncologist. Although many patients avoided certain types of information as a way of preserving hope, others felt the need for a complete picture of their disease status and the likelihood of cure in order to help them cope.

For these patients, more information helped to avoid the uncertainty associated with denial. The following interaction demonstrates how some patients probed the oncologist about their chances of survival. This seemed to reinforce their disease status and enable them to cope by confronting the 'reality' of their condition.

Out of 55 consultations with newly diagnosed patients, 10 had terminal illness (Duke's D cancer). Out of those 10 patients, 10 asked about their prognosis during the first consultation with the oncologist. In the remaining 45 consultations, no patients asked about their prognosis.

Dr Fenton: What do you understand has happened to you and why you're here?

Jason: They said (surgeons) they couldn't operate so they'll see what can be done with drugs.

Dr Fenton: There's a spot on the liver, so it's too large to be removed. Drug treatment seems a good idea but it shrinks the cancer for one in three people. It's not a curative treatment and it (the cancer) tends to flare up again. It flares up in months rather than years. Some people can have problems. Nowadays you may get injections or pills. You could get diarrhoea, mouth ulcers, hair loss is unusual, some people have rashes. You're a fit chap but it's not a guarantee. You must ask yourself if you want to have it, it's a personal decision.

Jason: If I don't have it how long would I last?

Dr Fenton: It could be the same with or without the treatment, it's months rather than years.

Jason: So it's (the cancer) quite big really?

Dr Fenton: Twenty nine centimetres.

Jason: Is there a lot of pain?

Dr Fenton: Pain's unusual. It's common for people to be generally frail. Your wife's suggestion of going away and thinking about it is sensible.

Jason: It (chemotherapy) doesn't extend your life?

Dr Fenton: If it does it's weeks rather than months. It hopefully improves quality of life at the cost of side effects.

Jason: It's not likely to last many more months?

Dr Fenton: It's a very hard question. It's likely to be many months rather than years.

Wife: Is it an attitude of mind? Will it give you a few more months?

Dr Fenton: Yes there is evidence for that.

Wife: Is there anything he can take?

Dr Fenton: I'm afraid not. There isn't a pill. I think it's talking and time.

Jason: There's quite a lot of the liver that's free of it?

Dr Fenton: Yes.

Wife: You can't cut it off?

Dr Fenton: I've never yet seen the surgeon to take it away.

(The patient and his wife stand up and the consultation ends)
(Observation 18, p2-3).

(Duke's D cancer of the caecum, married, shoe shop owner, 70)

This interaction demonstrates the patient's desire to form a clear picture of the time frame that is attached to his life. The oncologist informs the patient that he has months attached to his life and the treatment would not increase significantly the chances of survival. The clinician did not offer a prognosis until Jason requested details. It was Jason who probed the oncologist with questions about life expectancy, tumour size, and pain. The patient's wife even asked whether it would be possible to surgically remove the tumour, but the oncologist replied that this was not possible. Consequently, the patient was left in no doubt that his illness was very serious and that he was probably going to die within a few months. The patient asked these difficult questions in order to help him confront his condition even though the news was not good. Indeed, the patient seemed compelled to ask these questions as he suspected the serious nature of his condition. The following patient did not expect to be told that his condition was serious since the surgeon had previously informed him that he was clear of cancer.

Dr Fenton: What did Mr Bird (surgeon) tell you?

Andy: He said they've taken a sample (biopsy) but it's clear (of cancer).

Dr Fenton: The scan shows some shadow on your tail end. It's characteristic of a recurrence. When Mr Bird examined you he was certain about the recurrence. I must be honest with you, although the treatment will help it won't eliminate it completely.

Andy: Will that give me relief?

Dr Fenton: Yes. An operation will not help. Treatment will start in two weeks. You'll feel tired, a bit out of sorts. You can expect the pain to improve two to three weeks after the treatment. I must give you some pain killers – morphine pills and morphine solution. You must take them regularly and you should find that they'll work.

Andy: Is this serious as you're using morphine?

Dr Fenton: Yes I'm afraid. Can I see your list again for your laxatives?

Andy: I guess I'll reach three score and ten. I'm nearly 70. I get down quite a lot but you can't do anything about it can you?

Dr Fenton: (The doctor shakes his head slightly in response). (Observation 29, p1-2).

(Duke's D, rectal cancer, widowed, retired paint sprayer, 69)

Although Andy played a limited role in the interaction with the oncologist, he probed the doctor about the seriousness of his condition. He did not expect to be told that he had a recurrence but he asked the clinician if his condition was serious. Subsequently, Andy acknowledged the serious nature of his illness by stating that he will probably live for another year and that nothing else can be done to extend his life. The need for the oncologist to confirm the terminal nature of his condition was a way for him to finally accept his prognosis. David, also asked about his chances of survival during the consultation after the oncologist indicated to him the terminal nature of his illness.

David: How long was it (the cancer) there?

Dr Fenton: Could have been three years.

Daughter: It's so unknown. If the tumour shrinks how long will he have?

Dr Fenton: I can't say whether you'll be one of the five percent.

David: The cancer is in the bowel and in the peritoneum.

Dr Fenton: Yes.

*David: You're talking anything between twelve months and five years?
No chance of extending the five years?*

Dr Fenton: That's unlikely (Observation 24, p1-3).

(Duke's D, colon cancer, married, local government officer, 64)

The patient attended the consultation with the impression that his illness was curable. However, as the oncologist began to explain the serious nature of his condition David began to inquire about his survival chances. Although he knew that he had bowel cancer, initially he did not appreciate its advanced nature. As a result, he sought to clarify the extent of the disease as a way of reinforcing his understanding of the condition. During 'bad news' consultations it was common for patients to ask how long they were likely to survive. Derek Fowler also wanted to form a clear picture of his condition especially because the oncologist informed him that he was still not cured following his surgery.

Dr Hutton: You had the liver biopsy a couple of weeks ago?

Derek: Yes.

Dr. Hutton: At the time they thought it was normal?

Derek: No sign of cancer. They said there's maybe no cancer.

Dr Hutton: There's a small cancer in there. There were some tumour cells mixed in with the liver cells.

Derek: So I'm not cured? What do we do?

Dr Hutton: That's what we have to decide. We need a scan to see what's going on with the liver. We need to see what there is, to keep an eye on it. We have two options: keep an eye on it, and the other is to give you treatment right away. Although the treatment may shrink the tumour, there's no guarantee.

Derek: It would be a shame to leave the option of curing it having gone through the operation.

Dr Hutton: It may do nothing.

Derek: The treatment would clear up whatever's there?

Dr Hutton. The treatment would shrink it, but would not get rid of it completely.

Derek: If the chemotherapy is not effective, how long would I have to live?

Dr Hutton: In the order of a year. That all depends on how fast they grow. Generally they don't grow fast.

Derek: Does cutting it make cancer grow faster?

Dr Hutton: I don't think so. It would have made problems for you.

Wife: We understood from Mr Jacobs (surgeon) that he was 99% sure that there was no cancer.

Dr Hutton: He wrote back to say there's been a big change since the second biopsy.

Wife: We saw him after the second biopsy and he said that he was 99% sure there was nothing wrong.

Derek: If it does develop you could give us treatment that will not make me suffer too much?

Dr Hutton: Yes. You won't have any pain. It's not an area which causes any pain. Often there are no symptoms (Observation 33, p1-2).

(Duke's D colon cancer, married, retired, 76)

Derek was confused about whether he had been cured by surgery or if the cancer had spread to his liver because the surgeon and the oncologist were providing conflicting information. The oncologist informed Derek that the cancer had spread to the liver, which is why he began to ask how long he had to live and if the chemotherapy would cure him. Like David previously, Derek felt compelled to form a clear picture of the extent of his disease as a way of reinforcing to himself the true nature of his condition. The following consultation with a 74 year-old patient, provides a further example of how patients often felt compelled to ask about their survival chances during 'bad news' consultations.

Dr Fenton. Some of the lymph glands were involved, and that's a warning sign that the cancer had spread. They did a biopsy but found no cancer cells. The liver's most common for the cancer to travel. If the liver is involved then it's very serious indeed. We need to do a body

scan. It may turn out it could be very serious, that it could be the liver. I am very worried indeed.

Daughter. (To the patient) They didn't tell you at the hospital did they?

Dr Fenton. It's very important you book yourself into the clinic a few days after the scan.

Mathew. When will they do it?

Dr Fenton. Two to three weeks.

Mathew. That's it then. Doesn't sound too good.

Dr Fenton. It's a worry I'm afraid.

Mathew. It's a worry. Have I got it in the liver?

Dr Fenton. I don't know for sure.

Daughter. What will the chemotherapy do?

Dr Fenton. If the liver is involved then we can decide what to do. If it's not involved then we can discuss the ins and outs of treatment. But the chemotherapy is not terribly effective. One third of people benefit.

Mathew. So this irritable bowel was cancer?

Dr Fenton. It looks that way.

Mathew. When the doctor (GP) kept saying go and see the consultant, I said I don't feel ill. Are my days numbered?

Dr Fenton. I don't know, that's why I need to do the scan (Observation 51, p1-2).

(Duke's C cancer of the caecum, widowed, retired, 74)

At the start of the consultation, the oncologist informed Mathew that his condition might be very serious because there is a strong possibility that the liver had been affected by cancer. With this knowledge, the patient and his daughter enquired about the likely benefit of further treatment, but the oncologist suggested that chemotherapy was unlikely to help very much. Finally, towards the end of the consultation Mathew felt the need to ask if his days were numbered. However, Dr Fenton stated that the liver scan would provide a better indication of time scale. It is evident from

this consultation that when the oncologist suggests that the circumstances are serious, patients often feel the need to ask about time scale in order to confront the possibility of death.

The interview data revealed why most patients did not ask the oncologist about their chances of survival.

Graham: You might ask the question about how long I have to live, but you realise yourself that you can't put a date on any of it because it all depends. If it suddenly spreads then that's it (Interview 17, p17).

(Duke's B/C colon cancer, married, retired fire brigade chief, 63)

Graham did not ask about his survival chances because he realised that nobody can provide an accurate answer to the question, not even a cancer specialist.

It is evident from the following quotations that Angela and Joan did not ask their oncologist about their chances of cure and recurrence. Although they may have wanted to know the likely benefit of treatment, the oncologist was not considered an appropriate information source for them. The issue of survival time was obviously an important concern for them, but they avoided asking the cancer specialist.

Interviewer: With the surgery you know if it's been successful, but what about the chemotherapy?

Angela: What would they do if you're ill? They may take x-rays, but would they know if it recurs? That's what makes me wonder. How would they know? I would like to know about that, how would they know if it's cured?

Interviewer: Does that make you feel uneasy?

Angela: Yes. Would you have to complain or would they take scans? I expect they would monitor you to see if it's gone any further. But I was wondering, would they expect you to tell them if you were bad, or would they use scans to see if you were cured? (Interview 25, p7).

(Duke's C colon cancer, widowed, retired, 74 – Italian)

Joan: All you really want to know after you've been through all this and had it done, are you going to be cleared? Are you going to be alright? I suppose being my age, I'm seventy, the first thing you think when anybody says cancer, you think they're going to die, and I don't want to die, not yet (Interview 10, p7).

(Duke's C rectal cancer, widowed, retired domestic, 70)

Angela and Joan were concerned about the future outcome of their illness. Nevertheless, they did not ask the oncologist about their survival chances. Thus, the conclusion reached from these findings is that some informants avoided prognostic information as a means of preserving hope and optimism. Others, however, wanted to know about the likely outcome of their illness but were still too frightened to ask. In such cases, a different information source might have been more appropriate, for example, a clinic nurse or a counsellor.

Certainly, in some cases it was clear that informants were still recovering from the shock of their diagnosis. Consequently, they were not able to ask all the relevant questions.

Linda: The second time when I saw him he did then tell me what I wanted to know, because the first time I mean I couldn't really take it in because I was upset and it was a shock to the system (Interview 19, p22).

(Duke's D colon cancer, single, property developer, 55)

The process of diagnosing and subsequently mapping the course of a cancer is problematic since the disease is laden with uncertainty and change. Following their surgery patients often had a limited understanding of the extent and nature of their disease. Subsequent to arrival at the oncology centre, they were given information about their disease status, and patients reacted to this 'biographical disruption' in different ways. Patients who were terminally ill often asked their oncologist to provide them with details of their prognosis. However, in the majority of consultations patients rarely asked about their survival chances because they had no immediate desire to know, and because they preferred to maintain a positive outlook.

On the whole, this section has demonstrated that patients used these different strategies, of either confronting or avoiding 'bad news', as a means of managing certain emotions. In other words, they were able to manage fear, and in many cases maintain hope for the future.

II. The role of oncologists in treatment decision-making

Introduction

The first part of this chapter was primarily concerned with the way that patients with colorectal cancer perceive their role in the decision-making process, the factors which influence their decisions, and the type of information that they require. This part will illustrate more specifically the role of oncologists in the treatment decision-making process. The main themes described in this section are supported with dialogue which took place between oncologists and patients during the initial consultation. Pseudonyms were used in order to hide the identity of patients and oncologists. Most consultations were conducted by two oncologists during the study period: a male consultant in clinical oncology (Dr Tom Fenton who was approximately 35 years old), and a female senior registrar in clinical oncology (Dr Anne Smith who was approximately 40 years old). However, approximately 10 consultations were also conducted by a male Professor in clinical oncology (Professor Mark Hutton who was approximately 45 years old), and two female registrars in clinical oncology (Dr Jane Richards and Dr Victoria Bench who were both approximately 35 years old).

The oncologist's role in interpreting information

Some authors have given the impression that cancer patients interpret probabilistic information primarily with reference to their own lives and experiences, but little is mentioned about how clinicians may aid this interpretation process (Charles et al, 1998; Weeks et al, 1998). Studies suggest that patients also tend to view their own condition and treatment in an optimistic light, even when the evidence indicates the opposite. This is believed to be due to the patient's emotional need to maintain a sense of hope in the face of adversity. This issue was explored in the previous section. In addition, it is important to recognise that the medical profession plays an important role in influencing a patient's understanding of treatment benefit and their illness.

Levels of patient involvement within the interaction

So far, I have shown the various individual responses to uncertainty and the interpretation of risk and probability. In this section, I shall describe some of the ways in which this probabilistic information was divulged to patients. Thus, the aims are to illustrate the different *levels or degrees* of patient involvement in the interaction with the oncologist, to show why some patients are more active than others in negotiating decisions. During most consultations oncologists were attempting to explain the risks and benefits of treatment to the patient. It was often the way that such information was communicated, which led patients to express some degree of uncertainty and confusion. For some patients the lack of clarity in the communication process did not seem to be a problem, but for other patients the uncertainty posed a greater challenge.

The following passages of a dialogue provide an illustration of the way that patients become involved in the task of interpreting information. They demonstrate how the use of information by the doctor in the communication process influences decision-making. During the consultations 'negotiations' focus on resolving the issue of treatment 'effectiveness'. However, there are *degrees* of negotiation between the doctor and the patient.

The consultation narratives in this section were selected because they are representative of the range of consultations which took place during the observation study. Out of the 55 consultations that were conducted during the study period, 22 were categorised as involving a more 'active' negotiation between the oncologist and the patient (and often the patient's family), and 28 were regarded as involving a more 'limited' negotiation. 'Active' and 'limited' negotiations were defined according to the level of patient involvement in the consultation, as illustrated below. The following three consultation episodes illustrate both 'active' and 'limited' negotiations between the doctor and the patient.

The following excerpt from a consultation with a consultant oncologist (Dr Fenton) illustrates the type of language which one oncologist used to communicate the benefit of treatment to the patient. The patient is an 80 year old retired office clerk. The consultation lasted just 5 minutes.

Dr Fenton: It looks like it is cancer of the colon. The question is what to do now. What you have is a tumour on the right side of the bowel. When they looked on the microscope they found cancer in the lymph glands. They took them away and there was no evidence that there was any cancer left. But the cancer may come back or may not come back. The treatment is no guarantee. The problem is that the treatment is quite strong. The problem is that the treatment can be debilitating. The problem is that there is no guarantee. If you were 50 or 60 I would go ahead. The chances are that you have already been cured. If you were my father I wouldn't want you to have it. There is only a small benefit. In their 50's and 60's they should have it, in their 70's I think there's a

problem. The chemotherapy is pretty hellish. My advice would be to leave well alone.

Richard. A bit like my circulation problems. They could operate but it could make it worse.

Dr Fenton. It could give you problems that you haven't got. We'll leave you to the surgeon. Is that reasonable?

Richard. Thank you for your advice doctor (Observation 20, p1).

(Duke's C colon cancer, widowed, retired office clerk, 80)

During this consultation, the patient played a limited role. This was largely because the oncologist presented the decision-making problem to the patient, and also because he resolved it for him by advising against further treatment. The patient's lack of involvement could also be due to his old age (80 years old) and his willingness to accept the doctor's advice.

In the above example, the oncologist informs the patient that there is no evidence of any more disease following surgery. However, he also introduces an element of uncertainty for the patient by suggesting that the cancer may still return and that further treatment is not a guarantee against recurrence. Moreover, the oncologist wants to advise the patient against any more treatment due to his advancing age by claiming that treatment is not a guarantee. Consequently, the patient finds it easier to follow the doctor's advice and make a decision not to accept treatment. The task of interpreting some of the uncertainty surrounding treatment benefit was simplified for the patient, as the doctor explicitly advised against treatment. Thus, the task of interpretation was largely assisted by the clinician. This finding contradicts previously cited research which implies that the process of interpretation is carried out primarily by the patient (Gregory and Cotler, 1994; Parsons and Atkinson, 1992; Charles et al, 1998). These studies do not indicate that the process of 'interpretation' and 'explanation' is a joint activity between the oncologist and the patient. In contrast, the findings from the current study indicate that this process is clearly a reciprocal venture.

A similar consultation took place with a 75 year-old patient, who played a very limited part. The consultation lasted 10 minutes.

Dr Fenton. What do you understand what's happened to you?

Fred. Haven't got a clue.

Dr Fenton. What did they (surgeons) tell you?

Fred. A cancer.

Dr Fenton. The cancer has gone through the wall of the bowel and the lymph nodes are affected. The treatment isn't certain. You could come for injections. We could say it's a serious cancer but I think that I could make it worse. This has knocked you for six and we should leave well alone.

Fred. Thank you very much (politely).

Dr Fenton. Would you like to ask any questions?

Wife. He never put on weight since the operation.

Dr Fenton. Don't make it an issue (to the wife). I'm concerned about the problem down below. We'll get the surgeon to see you (Observation 4, p3).

(Duke's C colon cancer, married, retired engineer, 75)

The oncologist summarised the clinical problem to the patient and then provided his advice that treatment would not be of benefit to him. Thus, a negotiation did not even take place between the doctor and the patient in this case. Indeed, the oncologist did not encourage the patient to play a more active part in the decision-making process. Likewise, the patient did not display any desire to discuss the issue of treatment further. Certainly, the ages of the above two patients may have played an important role in the approach taken by the oncologist during the consultation. As both patients were over 75 years of age, the oncologist could have envisaged greater potential difficulties in their tolerating the treatment.

The following extract of a consultation is an example of a very different type of exchange between the doctor and the patient in which the patient plays a much more active role in questioning the doctor. This consultation was conducted between a 71-year old man and Dr Smith, and it lasted 45 minutes. The informant attended the consultation alone.

Harry: The fundamental thing before I go any further, are you, as a doctor, saying that I need more treatment or I don't need more treatment?

Dr Smith: No I'm not. I'm saying I'm uncertain. If you were Duke's C you would be advised to have it. As an A/B I would say no.

Harry: So we're in a grey area? We'll have to wait and see.

Dr Smith: We do things according to statistics. 60 to 70 percent of

Duke's B's survive five years. Duke's C is 30%. That's why we advise treatment. Chemotherapy will improve your chances. With Dukes D the cancer has already spread. If you were 50 I would have advised you to have entered into the study. Do you want to go away and think about it for a week?

Harry: I don't know. I never had this in my life. It seems like a big decision, in the context that nobody can say if it'll do any good or not.

Dr Smith: We can't see if there's tumour there-we work on probabilities.

Harry: The alternative is not to do it.

Dr Smith: If you had problems in the future we could treat you then.

Harry: I've never been a coward in my life and I would accept if I knew it was worth doing. The thing that disturbs me-the question of if it's worth it or not. If it is, I would say yes lets go. If it's not, then there's no point continuing. I don't know if I could talk it over with anyone? (Observation 6, p2).

(Duke's B colon cancer, widowed, retired mechanical engineer, 71)

This patient found it very difficult to decide whether the treatment was worth pursuing given that the doctor did not give a clear indication about the appropriateness of treatment. Indeed, the doctor admitted to the patient that she was uncertain about the decision. She claimed that she would be more certain about treatment if the patient had a more advanced tumour, and if he had been younger. Because he did not fit this profile, she felt that the patient had to make the decision for himself since it involved a value judgement. For the patient, this dilemma was a difficult one. The outcome of the consultation was that the patient decided to delay his decision to a later date. Nevertheless, the above conversation illustrates a 'negotiation' between the doctor and the patient that is aimed at resolving the uncertainty surrounding the benefit of treatment. In this example, the oncologist provided a summary of the likely benefit of treatment, which the patient attempts to interpret in order to decide whether it is worth pursuing. This was a difficult task for the patient, as the doctor did not provide any strong opinion regarding the best option.

The previous examples suggest that some patients take part in an 'active' negotiation with the oncologist in order to clarify their understanding of the information disclosed to them. However, for other patients the interpretation of such information was aided much more directly by the clinician. Thus, some patients did not feel that they needed to engage in an intense dialogue with the doctor in order to reach a decision. The process of dealing with uncertainty where treatment benefit is unclear is often a reciprocal effort requiring 'negotiation' and mutual interpretation. The

last narrative indicates that the level of patient involvement in the decision-making process is frequently restricted to resolving the issue of treatment 'effectiveness'.

Providing a treatment recommendation

The current study found, from data of clinic observations that the role of oncologists was central to the way that patients understood the benefits and risks attached to treatment. The observations also showed that the oncologist's role in communicating information to patients had a large influence on the decision-making behaviour of patients.

In the majority of consultations (45 out of 55), oncologists frequently offered a treatment *recommendation* to patients, and this was accepted in most cases. In consultations where the oncologist provided a treatment recommendation there was limited debate about the best treatment decision. The following consultation illustrates how a treatment recommendation provided by the oncologist reduces the need for the patient's involvement in a dialogue or a 'negotiation' with the doctor about the best course of action. The main reason for this is that most patients trust the doctor's advice and welcome the clinician's opinion. This consultation took place between a consultant oncologist (Dr Tom Fenton) and Gene - a 49 year old Masseuse who has a hereditary form of bowel cancer. She attended the consultation with her husband.

Dr Fenton. What do you understand by what is wrong with you and why you are here?

Gene. They cut out everything they could. They sent me here as a precaution.

Dr Fenton. They found tumour in the bowel and some changes in the bowel to see if there is a genetic component. They found a tumour in the liver.

Gene. It was in the colon.

Dr Fenton. That again was removed. We need to do a scan to make sure it's all been removed. It will be probably chemotherapy. The aim of that is to try to prevent it coming back.

Gene. There's a risk it could come back.

Husband. It's more or less what they already told us.

Dr Fenton. Your aunt had it?

Gene. When I was twenty five.

(The doctor conducts an exam on the couch, following which the patient gets dressed).

Dr Fenton. We need a scan to see what's going on. If all is normal then the treatment would be an injection of drugs for five days for the first week, and then three weeks off, for six months.

Husband. What does that consist of?

Dr Fenton. It takes 10-15 minutes to have it. An hour altogether. Some people can feel quite sick. People after the treatment can have worse side effects, diarrhoea or sore mouth. Some people have no side effects and others have more severe side effects.

Gene. Can I work?

Dr Fenton. Well what's your job?

Gene. I'm a part time masseuse.

Dr Fento. It depends on how you feel. You're at a higher risk of infection, so keep away from people who are ill. There's no reason why you can't (work).

Gene. I was thinking of going to France for a week on December 27th.

Dr Fenton. It's best to have a month or six weeks after your surgery. (To recover-so it's ok to go on holiday presumably).

Husband. The surgeon said there's no great rush. The sooner we do it the better. When she had a colonoscope they didn't find anything.

Dr Fenton. The scan will be in the next 2-3 weeks. We'll start the treatment in the new year.

Husband. What kind of a scan will it be?

Dr Fenton. A CT scan (Observation 32, p2-3).

(Duke's D colon cancer, married, masseuse, 49)

This consultation shows how the oncologist not only provided a treatment recommendation to the patient, but assumed that she would accept the offer. Once the oncologist made it clear that the cancer could return, the issue of chemotherapy treatment was not even raised as a question. Gene had accepted that the treatment was necessary to prevent recurrence. Thus, the consultation was fairly brief (17 minutes), and Gene's questions focused on the practical concerns of whether or not she could work and go on holiday. Thus, the deliberation was limited to a brief discussion about whether the treatment would interfere with Gene's work patterns and her holiday abroad. There was no discussion about whether treatment was appropriate and whether Gene was going to accept it. The following consultation provides additional evidence that when the oncologist provides a treatment recommendation, the level of patient involvement in decision-making during the consultation is limited to either accepting (as in the following case) or rejecting the treatment option. The interaction took place between a 75 year-old male patient and Dr Jane Richards, a registrar in oncology. The patient attended with his daughter-in-law, and the consultation lasted 34 minutes.

Dr Richards. You have a tumour which they completely removed and they took some glands and some were with tumour. Did they tell you?

Harold. No.

Dr Richards. It's a common finding. Chemotherapy would be useful. A large number of studies have been done in the USA. If you take 100 people, 50 with and 50 without, those with chemotherapy do a little bit better. It's not a huge difference but it's a difference. The chemotherapy is not an easy treatment to have.

Harold. I'm quite happy to have it.

Dr Richards. We need to make it a joint decision. You have it 5 days a week, once a month by injection. You have three weeks off and we do it for six months. Side effects tend to be worse when you're over 70. They're general tiredness, you tend to get diarrhoea, be off your food, sore mouth. You may feel queezy or nauseous. Some people get all of that in a big way, and we need to get them to hospital. And some don't get any. We would be monitoring your blood count closely. You're more likely to suffer from them if you're a bit older. The difference it would make to you in terms of beating the cancer is 1 in 10. It's possible that the op cured you already. The chemo will help 1 out of 10 people. It's a decision that you make as well as we make. You seem to be a fit chap. The options are not to do anything as you might already be cured, but we don't know.

Harold. I can say no, I can carry on as I am. If it comes back again I've got problems.

Dr Richards. If it comes back chemotherapy is still an option.

Harold. We should take the option (Observation 22, p1-3).

(Duke's C colon cancer, widowed, retired insurance broker, 75)

What is interesting about this consultation is that as the doctor begins to explain the advantages and disadvantages of chemotherapy treatment, Harry almost immediately claims that "I'm quite happy to have it". He could have been persuaded by the oncologists early emphasis that the treatment would be beneficial, "chemotherapy would be useful...if you take 50 people, 50 with and 50 without, those with chemotherapy do a little bit better". The quick decision that Harry made to accept the treatment suggests that he probably expected it anyway, but the oncologist's summary that the treatment is likely to be of some benefit persuaded him in favour of chemotherapy. Indeed, the oncologist then discussed the likely side effects that could result from the treatment, but Harry had already made his mind up by proclaiming "we should take the option". The consultation continues.

Daughter-in-law. The only problem he's got is I won't be able to bring him as I'm changing jobs.

(Dr. Richards goes to get an information sheet).

Dr Richards. This is a nationwide study. What we're not sure about is if we should give it a low dose or a high dose. We will phone up and they'll say whether you'll get the low or high dose. They're both effective but we don't know how much. You'll have to take some tablets. In the USA they are effective, in Europe we're not sure. This may increase the side effects. You may get the real thing or not the real thing. We just want to see what the side effects are due to the tablets.

Harold. I think I might as well have it.

Dr Richards. If you find you are suffering we can stop.

Daughter-in-law. You can stop. You should take the chance.

Harold. When do I start?

Dr Richards. I'll need to get the thing that will make you consent.

(Dr Richards goes to get a consent form but she returns without one).

The nurse co-ordinator is getting a consent form. So if you wait in the

waiting room. Any questions?

Harold. I can't drive?

Dr Richards. You can drive. It's a matter of personal choice. You'll see how you feel. You'll get more information as the thing goes on (Observation 22, p1-3).

(Duke's C colon cancer, widowed, retired insurance broker, 75)

This concluding part of the consultation shows that Harry's engagement in the treatment decision-making task is very limited. He has already decided to accept treatment, and the only issues which he wanted to address were again the practical issues when the treatment would start and whether he could drive his car whilst having treatment. Similarly to Gene, Harry wanted to accept the offer of treatment and his decision was simplified by the oncologist's recommendation that the chemotherapy would increase his chances of survival. The following consultation narrative is a further example of the extent to which the patient's decision-making task is simplified by the oncologist's advice that treatment would be beneficial. The consultation took place between Dr Hutton and a 53 year-old electrical engineer, who attended the meeting with his wife. The consultation was relatively brief, lasting 19 minutes.

Dr Hutton. Anyone in your family had cancer?

Peter. No.

Dr Hutton. Yep. I think the surgeon is right. You had the tumour removed. There are risk factors. One of the lymph nodes was with tumour which indicates a higher risk factor. Chemotherapy can reduce that risk of the tumour coming back. Those people who have the treatment also had the tumour coming back. We're not sure which is the best treatment. A drug called 5-fluorouracil is most effective and that can be more effective in combination with another drug called folinic acid which is the chemotherapy drug. We're involved in a trial. Some people have tablets in addition, and some don't. Nobody knows if the levamisole works. If you're happy with it we'd like you to take part.

Peter. I'm in your hands, so do it.

Dr Hutton. The treatment would be injections for five days and you would have three weeks off. The treatment would last six months.

Peter. Oh six months? He said six weeks (the surgeon).

Dr Hutton. The dose would be too great. The most common side effects are, a sore mouth, diarrhoea. We can give you tablets for the diarrhoea. Most people don't lose their hair. The treatment can affect your blood, which makes you more susceptible to infection. Some people get worse side effects than others, but we can reduce the dose. You're younger than average.

Peter. So something's on my side (chuckle). Does it take long? (Observation 17, p1-2).

(Duke's C recto-sigmoid cancer, married, electrical engineer, 53)

Even though the oncologist explains that the chemotherapy treatment may not be effective, Peter still was keen to have the treatment. Thus, the uncertainty surrounding the effectiveness of treatment was overshadowed by the doctor's recommendation that he should have the treatment, "if you're happy with it we'd like you to take part". He expressed his preference to accept the treatment course very early on in the consultation. Towards the end of the consultation Peter and his wife express some concern that the treatment might prolong his absence from work, and the likely side effects. However, they do not embark on a detailed debate about whether to undertake the treatment, since that choice has already been made.

Wife. He thought he would go back to work in January or February.

Dr Hutton. There's no reason why you can't work. It depends how you feel.

Peter. It is a stressful job-mentally. Will that be a problem?

Dr Hutton. You will probably get more tired than normal. If you can work part-time, that's best.

Wife. The side effects, are they more intense later?

Dr Hutton. It tends to be worse later on in the treatment.

Peter. Is that the dosage building up?

Dr Hutton. The body recovers 95% but not fully.

(At this point the patient agrees to the treatment and the consultation concludes) (Observation 17, p1-2).

(Duke's C recto-sigmoid cancer, married, electrical engineer, 53)

This section has shown that patients often follow the oncologist's advice if a treatment recommendation is provided. In many cases the decision-making task is straightforward where patients do not feel the need to embark on a long dialogue or negotiation with the clinician. Instead, they prefer to discuss practical issues such as the availability of hospital transport, or the length of treatment. However, the degree of patient participation, in cases when the specialist provides a treatment recommendation, does vary somewhat. Although on the whole, when the consulting oncologist provides a recommendation, the level of patient participation in decision-making tends to be lower than in cases when the doctor does not provide a recommendation. This will be illustrated in the subsequent section. The reason for this is that patients tend to trust the oncologist's judgement in the decision-making task, which often limits the need for their involvement.

Providing no treatment recommendation

The analysis of the observation data has demonstrated that when oncologists do not provide a treatment recommendation, the degree to which patients participate in the decision-making task with the doctor increases. In these circumstances it seems that patients become more involved in the decision-making task in order to try to elicit a recommendation from the oncologist. In 10 out of 55 consultations, a treatment recommendation was not provided, or the specialist refused to provide one. The consultation narratives below were selected because they are typical of the 10 consultations where the doctor provided no treatment recommendation. The following consultation lasted 21 minutes and took place between a 74 year-old woman and a consultant oncologist, Dr Fenton. The patient's daughter was also present at the consultation.

Dr Fenton. The chances of you having bad side effects increases over the age of 70. Diarrhoea, soreness of the mouth and tiredness. Two to three percent come to hospital. Whilst treatment can dampen down the cancer it cannot eradicate it entirely. Chemotherapy is not a guarantee. Even with treatment the cancer can return. You may already have been cured. When you're over 70 it's a more personal choice. One third of patients are cured by surgery. The chance of being cured in addition with the chemotherapy is eight to twelve percent on top of the 33%. As you get older the way you see it changes.

Angela. I know somebody who had a recurrence with the lymph glands.

Dr Fenton. It's a personal decision.

Angela. What do you think (to the doctor).

Dr Fenton. It's difficult.

Daughter. If she doesn't have it?

Dr Fenton. She'll be monitored in the usual way. The cancer could come back with the chemotherapy too. (The patient shows a picture that the surgeon drew for her, on which she shows the doctor the lymph glands that were involved by the cancer). That's why I think it's important you decide about the treatment.

Daughter. How long will she live without treatment?

Dr Fenton. It depends.

Angela. Do you think I should have it?

Dr Fenton. I really don't know. When you're 50 I'd have it, if you're 60 I'd have it, if you're 70 I don't know. It's personal. I think that you should go away and think about it.

Daughter. You don't know if she's cured?

Dr Fenton. It's all averages I'm afraid. The lymph glands were taken out.

Angela. Ooh.

Daughter. He took the lymph glands away but the cancer could have gone elsewhere.

Angela. I think we'll think about it.

Dr Fenton. In the end it really has to be your decision if you have it or not.

Angela. I was hoping you would advise me. If your mother was in the same position what would you advise?

Dr Fenton. I would probably not advise her to have treatment. It's a 8-12% increase in benefit. You have to think about it. It's one of the things where there is not a right or a wrong answer. It could go further without the chemotherapy and it could spread with the chemotherapy, but the risk is reduced (Observation 16, p1-3).

(Duke's C colon cancer, widowed, retired, 74 – Italian)

This lengthy consultation provides a typical example of the difficulty that some patients encountered in reaching a treatment decision where the oncologist did not provide a clear treatment recommendation. Typically, oncologists did not provide a treatment recommendation when patients were either over the age of 70, or if they had advanced disease. In these circumstances oncologists felt that the decision-making task was much more value laden and personal as the definition of 'treatment benefit' becomes a more subjective matter. For instance, people who are older might experience greater problems in tolerating six months' of chemotherapy, and due to their advancing age, they could die due to some other cause. Indeed, the oncologist did indicate in the previous consultation that the treatment decision for people over the age of 70 is a more personal matter. The oncologist provided a rather uncertain picture of the benefit of treatment by claiming that the cancer could return with or without the chemotherapy. Consequently Angela and her daughter engaged in a lengthy 'dialogue' with the oncologist to try to elicit a recommendation and negotiate a decision. Dr Fenton was extremely reluctant to provide a recommendation. However, he finally felt compelled to assist Angela in her decision-making task by claiming that if she was his mother he would not recommend treatment. Nevertheless, he reflected the problem back to Angela by stating that it was a decision, which only she could make, and that there was no right or wrong answer.

This example illustrates how the absence of a clear treatment recommendation can result in a prolonged discussion whereby the patient attempts to elicit the specialist's advice. Thus, the reason why Angela embarked on a lengthy dialogue with the oncologist regarding the benefit of chemotherapy treatment was to *avoid* having to make a treatment decision alone. The following consultation provides a further example of a prolonged 'negotiation' (lasting 46 minutes) between Dr Smith, a senior registrar, and a 71 year old retired mechanical engineer. Again, no treatment recommendation was given. Initially, the oncologist provides a summary of the pros and cons of chemotherapy treatment. The doctor paints a somewhat uncertain picture of the likely benefits of treatment by claiming that she is unsure whether chemotherapy will benefit the patient.

Dr Smith. Let me explain why the surgeon has referred you. When we look at tumours we look at them under the microscope. Some of the tumours are inside of the colon and have not gone through the wall. We wouldn't give anything for those. Others have gone through and glands are involved - such patients are prone to further problems later. You're in the middle. Where the lymph glands are involved we don't give anything. Those with the cancer that's gone through the wall we do give treatment. There's a question whether chemotherapy is of benefit. We would ask if you would consider going into a study where half are

randomised into chemotherapy and half into no chemotherapy.

Ronald. When I was in Frenchay I was told it was all taken away. I was in the B category and there was no spread and no lymph nodes were involved. Are you saying that there is no treatment available, only a possibility that chemotherapy is of benefit?

Dr Smith. It is a possibility that the tumour has spread. We have to balance whether chemo would benefit you against no chemo. I can't say whether there are any cancer seeds anywhere in the body. We can say, if we had a hundred people, that 60 to 70 would be fine without further treatment. If we gave chemo it would increase the 60,70 to 70,80.

At this point Ronald begins to ask questions and become involved in an extensive conversation about the benefits of treatment with the oncologist.

Ronald. I live by myself and if I have to come here every day - if I'm not going to be in good shape - then that's a paramount factor. The alternative is not to do it.

Dr Smith. The chemo will improve the chances by 5 to 10%. That's what we believe.

Ronald. That's positive, but that's purely a statistic. I'd like to talk it over with the GP.

Dr Smith. If you say yes, there's a 50% chance that you won't have it.

Ronald. So where does that leave my chances?

Dr Smith. I can only go by what previous patients have done before. 6 to 7 out of 10 patients will live five years. We look at five year survival.

Ronald. We are talking about a statistical thing rather than a clinical?

Dr Smith. Yes. You have a 6 to 7 out of 10 chance of living five years or longer.

Ronald. By then I might be ill and it won't cure.

Dr Smith. It's very difficult.

Ronald. It would be easier if you said, if you have this done then it's A,B,C,D etcetera. But we don't know one way or the other.

Dr Smith. I agree. We have twelve weeks from the op in which to make a decision. Do you want two weeks?

Ronald. Yes.

Dr Smith. It's a very difficult thing.

Ronald. I don't have any problem that it is a guinea pig job. What I find hard is that there is nothing to say whether it'll do any good or not. The chances of anything returning will take five years? There's nothing to say that the treatment will change the statistics?

Dr Smith. It's likely to change them, but it's no guarantee.

Ronald. What you're saying about the side effects-coping with living by myself may be a problem.

Dr Smith. We need to warn patients that these are possible side effects.

Ronald. A-you may not be selected, B-you've got to go through it and C-nothing may change anyway?

Dr Smith. Your chances are likely to be better than if you hadn't.

Ronald. I get a pain at the bottom of my stomach, what is it?

Dr Smith. Probably the nerves.

Ronald. I don't think there's anything else. It's all about survival.

Dr Smith. Yes.

Ronald. As things stand at the moment you can't say that everything has been taken away. Once he (surgeon) said that lymph glands were clear I thought it was all clear, but now it's less clear. I'm normally a very decisive person and I want to think about this. I didn't expect this.

Dr Smith. You expected me to say, you have to have this?

Ronald. Yes. It would be easier to deal with. Enough said. In terms of pure logic it's a question of whether anything's worth pursuing or not. Can I go back a minute. If there was going to be a return, it may show up in about three years or near about three years.

Dr Smith. Within.

Ronald. So it could be six months?

Dr Smith. Unlikely, but possible. If it was going to it would come back in five years.

Ronald. You hit on the crucial bit, "if it was going to".

Dr Smith. About ten years ago we were doing similar studies with patients with breast cancer.

Ronald. You've answered all that you could. If I can see a purpose in something.....It's difficult making decisions. It's when you're in no man's land that it becomes very difficult (Observation 12, p1-3).

(Duke's A/C colon cancer, single, retired mechanical engineer, 71)

This consultation is an example of an intensive dialogue between the patient and the oncologist, which resulted due to the inability of the clinician to provide a treatment recommendation. As soon as it became evident to Ronald that the likely benefit of chemotherapy treatment was uncertain, he engaged in a long conversation with the oncologist in order to elicit her recommendation. The task of reaching a decision proved to be extremely difficult for this patient. Indeed, the oncologist stated to the patient at one stage, "you expected me to say – you have to have this", to which Ronald replied "Yes. It would be easier to deal with". This indicates that the patient would have preferred the oncologist to express an opinion about the best way to proceed. Ronald also felt that the information which the doctor divulged to him about the possible 5 to 10% improvement in five-year survival, was in his own words "purely a statistic". Thus, for Ronald the disclosure of statistical information was insufficient to aid him in his decision, and what he was seeking was the doctor's reassurance that treatment was worth undertaking. Indeed, Ronald's greatest concern was that the decision-making task was largely left to him, and it is in these uncertain situations that he would have appreciated some guidance – "It's when you're in no man's land that it becomes very difficult".

So far, the evidence in this section shows that oncologists play a central role in treatment decision-making, and they often influence the degree to which patients participate in the decision-making task during the consultation. The extent to which clinicians provide a treatment recommendation to patients plays a central role in affecting the nature of the interaction. The evidence shows that when a treatment recommendation is provided, the level of patient participation during the consultation is limited and most patients do not become involved in a prolonged discussion. The reason for this is that when a treatment recommendation is provided, patients do not feel the need to as the decision is often made implicitly. However, it is important to note that there are degrees of patient involvement. In some cases, when the patient does not agree with the doctor's recommendation, a dialogue does ensue between the two parties.

In situations where a treatment recommendation is not offered by the oncologist, the decision-making task is often prolonged and the patient's level of involvement is greatly increased. In these circumstances patients often want to avoid having to make difficult decisions alone. Consequently, they attempt to elicit the oncologist's recommendation. This process can be a protracted affair and one where a treatment decision is often left unresolved. The evidence suggests that when patients are told that treatment benefit is uncertain or marginal, patients often question the purpose of chemotherapy. In addition, patients may feel pressure to accept treatment, even if treatment benefit is limited, as patients want to avoid future blame for not maximising the treatment options. This supports the observation that patients feel compelled to accept chemotherapy, even when they understand that treatment will be of marginal benefit. Due to the absence of a clear recommendation, and because they feel they should take treatment as a precaution, patients frequently engage in a long dialogue with the clinician, as a means of clarifying the issues.

In the first part of this chapter, some informants claimed that they played a very active part in decision-making and others felt that the decision was a joint effort between them and the oncologist. However, the observation data presented in the latter part, indicates that some patients played an active part in the decision-making task, especially when the oncologist did not provide a treatment recommendation. Although in the majority of cases where the clinician provided a treatment recommendation, patients played a limited part in decision-making. Thus, to some extent, the observation and interview data show conflicting points of view. It could be that patients felt that they had played a greater role in the decision-making task than they actually did.

Conclusion

The findings from the study indicate that informants adopted various 'strategies' to help them understand the risks and benefits associated with cancer treatment. Informants interpreted the information communicated to them in one of several ways. Some translated the uncertainty surrounding their illness and treatment in simplified terms, where the potential outcome of therapy was reduced to alternatives such as 'success' or 'failure'. Other informants adapted the information that they were given in a way that made greater sense to their own lives. In these circumstances, acceptance of treatment seemed to be a rational decision, as it could improve their chances of survival. However, most informants tended to interpret this information in terms of a positive outcome for themselves, and this helped them in their adjustment to their illness. Similar

results have been found in other quantitative studies of treatment decision-making in cancer (Mackillop, 1988; Siminoff et al, 1991).

In their qualitative study examining the role of breast cancer patients in decision-making, Charles et al (1998) concluded that individuals interpreted information in categorical terms as a way of coping with uncertainty. Their findings indicated that this interpretation process was a 'cognitive' one, and which was carried out largely in isolation from interactions with oncologists or other members of the patient's social network. The current study suggests that the process of interpreting probabilistic information was influenced, not only by the need of the informants to maintain a positive outlook, but through their interactions (and 'negotiations') with oncologists and family members. Further, their search for 'reassurance' from medical staff, as well as from family and friends, influenced their interpretation of clinical information. Their interpretation was shaped by a reciprocal exchange (please refer to part II of this chapter) involving the participation of the oncologist, the patient, and often the patient's family. Williams and Popay (1994) also stress the importance of examining the connections between 'expert' and 'lay' knowledge, and how people configure the consequences of illness within the context of their own lives.

This study found that towards the end of treatment, people's perceptions of risk and benefit change. This change is reflected by their frustrations that stem from the uncertainty surrounding the outcome of treatment. A conflict takes place at this point between their positive outlook and the uncertainty that underpins their cancer diagnosis. The patient's experience is one where uncertainty exists throughout the treatment course, and which tends to re-surface towards the latter stages when the question of treatment 'effectiveness' is revisited by the patient. There is, therefore, a need for clinicians to keep their patients closely informed throughout their treatment experience. This in turn, will help them manage their uncertainty and enable them to maintain a positive outlook.

The findings indicate that many informants were not passive recipients of technical and scientific information. They often interpreted and evaluated information so that it added greater meaning to their lives. However, this process of interpretation was carried out together with the oncologist and members of the informant's family. This finding suggests that usually patients do not make decisions on the basis of the 'rational' model of decision-making, in which decisions are reached on the basis of scientific evidence (Brock and Wartman, 1990).

Another issue examined in the study, was to what extent patients felt that they had a treatment choice, and how they perceived that choice. In this study, the scope for involvement in decision-making was limited to whether patients would accept or reject the treatment option. Decision-making did not extend to choosing between different treatment alternatives as is the case with many research studies (Ashcroft et al, 1985; Ganz et al, 1985; Ward et al, 1989; Degner and Sloan, 1992; Deber, 1994; Sandison et al, 1996). The findings indicate that informants were usually given the choice to accept or refuse treatment. However, they often claimed that the

choice was not an entirely 'valid' one, as refusing the treatment was not a realistic option. Their desire to improve their chances of survival outweighed the perceived risks inherent in cancer therapy. This finding indicates that informants often played a limited part in the decision-making process. Treatment symbolised a chance for many to maintain some confidence that their illness would be overcome, and it allowed them to feel part of a system that was helping to make them well again. Thus, greater recognition should be attached to psychosocial factors by oncologists during the decision-making process, especially in cases where the preferences of patients conflict with medical advice.

The analysis of the follow-up interview data also indicates that, subsequently, informants attempted to re-evaluate their decisions. According to the study conducted by Charles et al (1998), patients used a normative language of 'right' and 'wrong' to evaluate the decisions that they had made. However, the current study found that towards the end of treatment most informants did not know if they had made the 'right' decision, as the outcome of their treatment was uncertain. This finding also indicates that some informants may have adjusted to the uncertainty surrounding the outcome of their illness.

The study also addressed the role that informants preferred for themselves and for their oncologist. The findings show that most informants preferred to be given an adequate explanation of what the treatment options entailed. However, they also wanted the oncologist to *advise* them on the best course of action. To this extent, the roles of the doctor and the patient were often clearly defined by the informants, whereby the clinician provided the advice and the patient had the final say. So, the exchange between the doctor and the patient was often reciprocal, but the process of technical problem solving was usually carried out by the clinician. Many informants took part in evaluating the decision with friends and family in order to strengthen their confidence in the decision that they had reached. Thus, the decision-making (or decision evaluation) task continued to take place beyond the medical arena. A 'shared' role in decision-making often gave informants a sense of control over the management of their illness since they were able to decide on their treatment, and then re-assess the decision with friends and relatives. Although their immediate input during the consultation was often limited to accepting or refusing treatment, their subsequent involvement in evaluating their decision with friends and family was more substantial. Therefore, it is important that patients are given an adequate supply of relevant information which they can subsequently draw on to reassess and interpret their decisions.

The study investigated the information needs of participants and how information was transferred between the patient and the oncologist. The findings indicated that informants demanded honesty from their clinician. This gave them the ability to participate more freely in decision-making with the doctor, to strengthen their confidence in that decision. Many informants desired information and honesty from the oncologist in order to give them a sense of control over the management of their illness. Informants also wanted to be reassured with information and

advice, in order to help them to overcome fear and maintain hope. In many cases the need for reassurance was as strong as the need for information. The desire to understand what was happening coupled with the need to feel reassured and comfortable about the decision, was very important for the informants. Most informants wanted some involvement in the decision-making process largely to help them feel reassured that they had made the best choice.

The study also showed that there was a need to provide patients with continuous information about their progress in order to help them accept some responsibility for the management of their illness. Much of the research which has been conducted on decision-making in cancer (Beisecker and Beisecker, 1990; Chadwick et al, 1991; Friedman et al, 1994; Elit et al, 1996) has limited its focus on the initial treatment decision. However, evidence from this study suggests that a longer-term approach to research is needed. It is important to take into account, not only the issues involved in the initial decision-making process, but also the consequences of the decision and how the patient's feelings may change.

Social class differences were not identified in this study, but the impact of employment and family composition did play a significant role in informants' decisions. Informants who had access to support from close relatives were more likely to accept the taxing treatment regimen. However, those with limited support often declined the treatment because they did not feel that they would cope. Families also often encouraged patients to have treatment even when they were reluctant to do so. The availability of support from relatives provided a context in which patients were able to discuss the possibility of treatment. Those who did not have relatives or who lived alone could only draw on the oncologist's advice. Also, certain informants decided to accept treatment 'on behalf' of their relatives. Informants wanted chemotherapy because they had children or grandchildren, and this gave them a good reason for accepting a long course of treatment.

Age also played an important role in the decision-making process. 'Older' informants were more likely to embark on a deliberation with the oncologist about the pros and cons of treatment, because to them maintaining a good quality of life was often as important as a longer life, and sometimes even more important. Thus, for them it was often more difficult to decide if the treatment was 'worth' it. 'Younger' informants were more likely to reach a quick decision regarding treatment because the most important factor for them was to maximise their chances of survival. The issue of 'quality of life' was not as central to them as it was for 'older' informants.

Men and women did not differ significantly in their perceptions of decision-making or their role in the decision-making process. The only exception seemed to be regarding the question of treatment side effects. Women were more averse to accepting treatment because of the likelihood of certain side effects such as hair loss, nausea and diarrhoea, which could potentially affect their body image and result in social stigma. On the other hand, men did not consider the possibility of side effects as a major concern. They did not relate the likely side effects to the social and

physical disruption that they might cause, as women tended to do. This gender difference might partly be explained with reference to men and women's domestic circumstances. Men might have been more likely to receive a greater level of support from relatives and spouses. In contrast, more women lived alone, and might have felt less able to expect their close relatives to provide such support for the duration of six months. For this reason the issue of side effects may have been more salient for women.

The study found that emotions play some part in the decision-making process. Informants invested a high level of trust in the oncologist, which often helped to simplify the decision-making task for them. The degree of trust in the therapeutic relationship was often subject to change or re-evaluation, throughout the course of the doctor-patient relationship. Informants also worked hard to maintain hope and suppress fear, and these factors enabled them to accept the offer of treatment more readily. They secured their sense of hope in a positive outcome by avoiding prognostic information, which could potentially disrupt their optimism. Some terminally ill informants felt that 'reinforcement' of their illness helped them to cope more successfully than avoidance. They did this by seeking clarification from their oncologist about their prognostic status, enabling them to plan ahead in view of the inevitability of death. For these informants, the issue of hope was no longer relevant. It is concluded that patients may require different types of information, in line with the changing nature of their illness. When hope is no longer available patients may require information about time scale as a way of facing the inevitability of death.

The second part of this chapter illustrated the different degrees of patient involvement in the decision-making process, and that the doctor-patient interaction is frequently concerned with issues of treatment effectiveness. The analysis also demonstrates that the way in which clinicians divulge information can have a considerable bearing on the decisions made by patients. In the absence of a treatment recommendation cancer patients are more likely to play an 'active' part in the decision-making task with the oncologist. This is largely due to their trust of the clinician's judgement and the desire to avoid having to make decisions alone. Conversely, the study found that when a treatment recommendation is offered patients feel less obliged to participate in the treatment decision-making task. However, on the whole, most patients desired clear guidance from their specialist in order to help them reach a treatment decision.

CHAPTER 8

DISCUSSION AND CONCLUSION

Introduction

This chapter discusses the implications of the findings and their relevance to the research literature. The current study sought to investigate the nature of the treatment decision-making process in colon cancer, and the extent to which patients wanted to be involved in this task. The findings suggest that treatment decision-making between the patient and the oncologist is often a very complex process that cannot be understood as one that is either dominated by the doctor or the patient. Indeed, decision-making is frequently carried out as a shared process between the doctor and the patient. The degree to which the patient participates in this process is often determined by the way that clinical information is communicated to him or her, and also by how far the patient is prepared to follow the doctor's recommendation. Certainly, one of the factors which often encouraged patients in this study to ask questions and negotiate decisions with their oncologist, was the way that they understood the scientific information that was communicated to them. This chapter discusses the application of the findings and demonstrates their relevance to treatment decision-making in oncology.

Patients' perceptions of decision-making

The findings from this research indicate that certain communication barriers often exist between oncologists and patients with colorectal cancer. As a result patients tended to simplify the information that they received in a more positive way, in order to help them make sense of unfamiliar terminology. To some extent, this finding is supported by studies carried out on peoples' perceptions of genetic testing for certain heritable conditions (Gregory and Cotler, 1994; Parsons and Atkinson, 1992), as well as those conducted on cancer patients (Mackillop et al, 1988; Charles et al, 1998; Weeks et al, 1998), where patients interpreted risk related information in a more certain way. Some studies have shown that cancer patients sometimes interpret information in a 'dichotomous' way (Mackillop et al, 1988), and others have reported that patients view complex information in terms of a positive outcome for themselves (Weeks et al, 1998). This is often the case even when the prognosis is very poor. This suggests that the information that patients receive may not be communicated effectively by the clinician, or that they may interpret information differently from the doctor.

Although patients were able to interpret the benefit of treatment in a more positive and certain way during the initial decision-making task, the question of treatment 'effectiveness' was left largely unresolved. What many patients failed to realise as they approached the end of their therapy, was that there was no clear way of assessing the success of treatment. Consequently, it was no longer easy for patients to maintain a positive outlook.

The findings show that initially, oncologists played a central part in advising patients on whether to accept or refuse treatment. It was partially this advice which helped them to interpret the risks and benefits of treatment in a more manageable way, and to overcome the uncertain nature of the information which was presented to them. In contrast, other studies have found that the process of interpretation of information is simply a 'cognitive' activity, whereby patients make sense of information without any external input from the doctor (Parsons and Atkinson, 1992; Rasinski et al, 1994; Charles et al, 1997; Charles et al, 1998). For instance, Charles et al (1998) found that breast cancer patients understood their survival chances according to information obtained from friends or relatives with cancer. This behaviour is sometimes referred to as the 'availability bias', whereby individuals assess their illness by comparing it to similar experiences of friends and relatives (Tversky and Kahneman, 1974). All of the studies cited were based on interview or questionnaire data, without any direct observations of the actual decision-making encounter. This may explain why Charles et al (1998) concluded that the process of interpreting information was primarily a 'cognitive' activity. More observational studies of the

doctor-patient interaction are important in order to provide data on what actually takes place during the clinical encounter.

As reported above, the communication style of the clinician can reinforce the patient's sense of hope, or alternatively it can increase the patient's sense of uncertainty. The findings show that oncologists need to strike a difficult balance between disclosing the 'truth' to patients, and communicating it in a way which patients can comprehend. The study found that this process is seldom carried out effectively, mainly because the advantages and disadvantages of treatment are rarely clear-cut. The findings also indicate that patients want the oncologist to provide a treatment recommendation. However, this is problematic, again because there is rarely a 'right' or a 'wrong' decision to be made.

The analysis of the interview data indicates further that although the decision-making process is heavily laden with uncertainty, patients sometimes engage in a dialogue with the oncologist in order to 'negotiate' an agreement about the best treatment option. It is through this process of 'negotiation' and communication that the initial uncertainties about the benefits of treatment are temporarily resolved. Thus, through communicating with the clinician, patients were able to make more clear assessments about the information that they received, including whether treatment was beneficial or not. In essence, the task of 'processing' complex information was largely assisted through a mutual exchange of information between the cancer patient and the oncologist.

However, this does not mean that the uncertainty surrounding the patient's condition and treatment became resolved. Rather, the decision-making task became simplified for the patient. It is not surprising that patients found it difficult, if not impossible, to come to a decision about treatment after a single meeting with an oncologist, given the complex nature of the information that they were required to interpret. Some studies have reported that doctors sometimes withhold certain types of information from patients in order to protect them from 'bad' news (McIntosh, 1976), or to assert their control over the therapeutic encounter (Marmot, 1996). Other studies have also reported the inevitability of the existence of uncertainty in chronic illness, as the process of reaching a diagnosis and treatment decision can often involve a prolonged period of assessment and speculation by both the doctor and the patient (Adamson, 1997). As a result, cancer patients should be given more time in which to decide on the treatment options presented to them, rather than feeling pressured to make an immediate decision.

The issue of treatment ‘choice’

Studies carried out on the decision-making practices of cancer patients have predominantly focused on the reasons why patients choose one treatment among several alternatives (Wilson et al, 1988; Slevin et al, 1990; Ganz et al, 1992; Long, 1993; Chapman et al, 1995). When faced with the possibility of various treatment alternatives, as in the case of early-stage breast cancer, patients often feel that they have several options to choose from. However, in the current study many patients felt that they did not have a meaningful choice, since the decision was restricted to simply accepting or refusing the offer of a single treatment option.

Many patients wanted to undergo treatment in order to maximise their chances of survival. However, some patients wanted to protect themselves from any future blame for not accepting the treatment option if the disease recurred. Others wanted to have treatment because it offered them reassurance and access to information, which in turn played an important part in helping them to assert some degree of control over their illness. The potential harmful effects of treatment were often perceived to be outweighed by the possible benefits of longer survival.

Several studies investigating patients’ decision-making preferences found that breast cancer patients often chose radical mastectomy rather than breast conservation treatment, in the fear that the disease could recur if radical ‘measures’ were not employed (Wilson et al, 1988; Slevin et al, 1990; Long, 1993; Chapman et al, 1995). One study of the treatment preferences of women with advanced ovarian cancer found that most patients opted for the treatment which offered the longest survival benefits, even at the expense of toxic side effects (Elit et al, 1996). Even terminally ill patients have been shown to demonstrate a remarkable desire to defy the odds by continuing the ‘fight’ against their disease (Yates et al, 1993; Brown et al, 1994; McQuellon et al, 1995; Yellen and Cella, 1995).

Patients also tend to have a very positive view of their own illness and the likely effectiveness of treatment (Charles et al, 1998; Weeks et al, 1998). The findings of the current study strongly support the view that bowel cancer patients, even after having undergone surgical resection with ‘curative’ intent, feel that they have no choice when it comes to chemotherapy treatment. Indeed, many patients claimed that they were expecting to receive chemotherapy, even when they did not understand clearly what it involved. This was simply due to the fact that they were referred to an oncologist.

Studies investigating peoples’ perceptions regarding the likelihood of inheriting cancer or other heritable conditions, found that people tend to draw on their social context and experiences when interpreting their risk status (King et al, 1993; Richards et al, 1995; Richards, 1996). These studies indicate that individuals do not have a scientific understanding of clinical matters, instead they draw on personal experience and their social context to provide logical interpretations of

risk. The current study found that patients did not necessarily make treatment decisions on the basis of the detailed information about the risks and benefits of treatment. Patients often accepted the oncologist's interpretation of the situation, as well as relating the offer of treatment to their personal circumstances and experiences. This latter scenario is particularly evident in cases when informants rejected the oncologist's treatment recommendation. In such cases, the patient's decision to refuse the doctor's advice, was often based on underlying personal and domestic reasons, such as the presence or absence of young children for instance.

The process of interpretation, which was aided by the clinician, was an attempt by patients to understand complex information in a more definite and certain way. If uncertainty occurred, patients often engaged in a dialogue with the doctor in order to overcome that uncertainty. The patients' desire to follow the doctor's treatment advice enabled them to view a decision in an optimistic light, in their belief that the clinician would not act against their best interest.

Following their course of chemotherapy some patients showed signs of uncertainty about the likely effectiveness of their treatment. Whereas initially they were more positive about their decision, subsequently they indicated some uncertainty about whether treatment had been the 'right' option to take. This suggests that towards the end of treatment, patients were able to adjust to their illness and to accept some of the uncertainties associated with a cancer diagnosis. Previous studies have found that patients usually believed that they had either made the 'right' choice or the 'wrong' choice (Charles et al, 1998). They were either satisfied with their decision or they were dissatisfied. This could be due to the fact that the majority of studies have not explored patients' long-term views about decision-making. Consequently, no previous study has found that cancer patients express uncertainty about their initial treatment decision, when asked several months or years following treatment. To this extent, this finding is new.

The above findings indicate that clinical information can be communicated successfully to patients, but patients may not be able to comprehend the information given to them at the initial consultation. This suggests that patients need to learn about their condition and its treatment, and have greater experience of the disease before they can adopt the clinical point of view. Much of the literature has referred to the decision-making task as a 'cognitive' process, and one that depends on an effective communication of information by the doctor. However, this study indicates that a patient's understanding of his/her illness and treatment changes with time. Therefore, more longitudinal research needs to be conducted to investigate patients' long-term views of treatment and decision-making. Such an approach could provide a greater insight into patients' changing perceptions, but also it could help to provide a better understanding of the process by which information is transferred from doctor to patient, and the way that patients interpret complex information after they have had time to 'digest' it. Such data could also give clues as to the most effective means of communicating technical information to patients.

‘Rational’ decision-making or ‘interpretative’ decision-making?

The ‘rational’ decision-making model, as advocated by Brock and Wartman (1990), assumes that the process of information transfer from doctor to patient is unproblematic. The information that is communicated to patients becomes internalised and utilised to make treatment decisions (see figure 4). Thus, the patient is considered to be an ‘empty vessel’ ready to be ‘filled’ with scientific information. Such models of the doctor-patient relationship assume that doctors will have their patients’ best interests at heart all of the time, and that patients internalise the information without any problems. However, one study has shown that patients do not just ‘receive’ information without participating in the interpretation and evaluation of that information (see figure 5 for representation of this interpretative model). Instead, patients make sense of information by relating it to their everyday lives so that it has personal meaning, and one of the ways in which they do this is by processing the information in a ‘dualistic’ way (Charles et al, 1998). The only difficulty with this model is that it assumes that the interpretation process is largely a ‘cognitive’ activity, incorporating the patient’s values, beliefs, and perceptions, but neglecting broader factors.

It is evident from the current study that this interpretation process is also significantly assisted by the doctor’s evaluation of the information. Indeed, it is the way that the doctor informs the patient which enables the patient to relate the information to his/her everyday experiences and beliefs. Thus, the doctor’s role in helping the patient to interpret the information, sometimes through a ‘negotiation’, is vital to any understanding of the decision-making process (see figure 6). Very few studies have attributed much significance to the cancer specialist’s role in communicating information to the patient (Liberati et al, 1990), and no studies have shown that the oncologist plays a central part in interpreting information for the patient during the actual decision-making task. The primary role of the clinician in aiding the patient’s interpretation of the information, which was found in this study, is new.

Figure 4: *Model of rational decision-making*

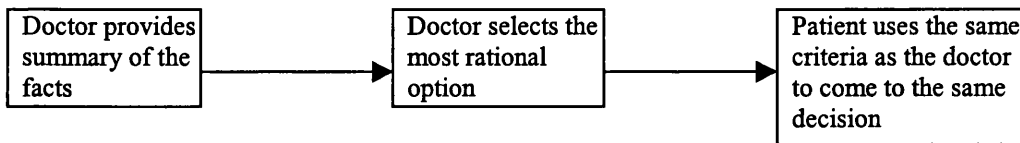


Figure 5: *Model of 'interpretative' decision-making*

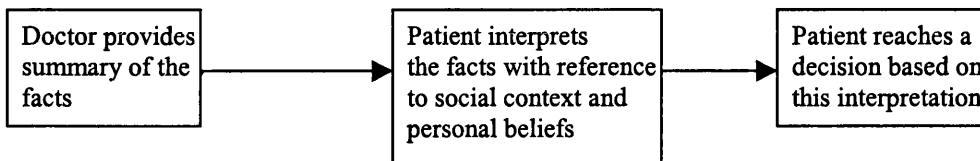
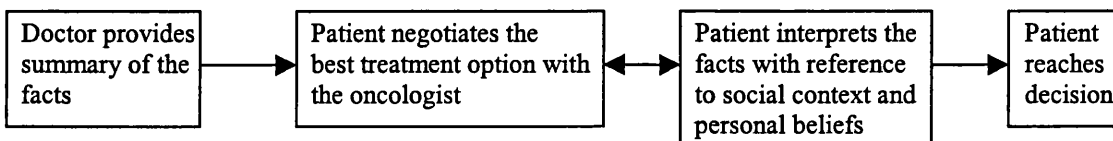


Figure 6: *The 'negotiation' approach to decision-making*



Role preferences in decision-making

Existing research on the decision-making practices of cancer patients shows a lack of consensus about what 'decision-making' actually involves. Some authors have referred to the task of 'decision-making' as a separate process from 'problem-solving' (Deber, 1994), whereby the former activity relates to the way that treatment is chosen, and the latter refers to the process which leads up to that choice. However, others have stressed the importance of separating the process of information sharing from the task of decision-making (Fallowfield et al, 1995; Marteau, 1995; Ong et al, 1995; Fallowfield, 1997). Just because some patients are becoming more active in the consultation, does not necessarily mean that they are playing a greater part in the decision-making process. Indeed, many patients do not want a greater role in decision-making (Sutherland et al, 1989; Tabak, 1995; Johnson et al, 1996; Pierce, 1993; Reaby, 1998), and a significant number of studies have reported that patients prefer a shared role (Ward et al, 1989).

However, what 'shared decision-making' involves in practice has not been fully explored by the majority of studies either. There is evidence that cancer patients want their clinician to provide a treatment recommendation (Ashcroft et al, 1985). Others have shown that cancer patients are 'reactive' rather than 'proactive' in the consultation with their doctor (Siminoff et al, 1989). One study also found that the doctor's perception of how much the patient wants to participate in decision-making is inconsistent with that of the patient (Degner et al, 1997). Consequently, it seems clear that more research is required to explore whether patients do in fact prefer a shared approach to decision-making, and what such an approach would entail. The current study has to some extent attempted to answer this question.

The findings from this study indicate that patients, far from wanting a passive role in decision-making, largely preferred a 'shared' approach. However, they often expressed different ideas about what the term 'shared' decision-making meant for them. Certainly, for some patients the decision to follow the doctor's advice unequivocally was in itself a form of participation even though they themselves did not express a strong viewpoint. Others decided that a greater level of participation in the decision-making process was the best strategy for them. However, the majority of patients preferred the clinician to provide a treatment recommendation.

The clinic observations revealed that oncologists often declined to make a management recommendation in cases where treatment was 'unclear' or contentious. For instance, terminally ill patients and those over the age of seventy, were often encouraged to decide on the treatment for themselves after the oncologist's presentation of the 'facts'. Conversely, in cases where treatment was indicated to be of 'clear' benefit a recommendation was usually offered by the consulting specialist. It was evident from the consultations that when patients were encouraged to make the treatment decision for themselves, most found this task extremely difficult. They often persisted in their attempts to gain firm advice from the doctor. This type of decision-making could be described as a joint activity with patients given a major role. Although, it was evident from the findings that most patients did not desire this major role nor the responsibility that accompanied it. The implications are that patients should be given greater guidance by the doctor in reaching a decision, especially when the evidence is ambiguous. Oncologists should not abdicate responsibility from making a treatment recommendation in cases where the evidence is unclear. Instead, they should encourage patients to think through the dilemma with reference to their values and preferences.

For many patients who participated in the observation study, treatment was considered to be of 'clear' benefit, and the consulting oncologist usually provided a treatment recommendation before any decision had been made. These patients participated in a different form of 'shared' decision-making with the oncologist. Having listened to the doctor's advice, patients were able to understand the treatment decision much more clearly. Thus, their role often involved simply agreeing to or rejecting the doctor's recommendation and their level of participation in decision-

making was often limited. In this scenario, it was often the oncologist who carried out the technical 'problem-solving' tasks prior to decision-making.

It is evident that the participants in this study wanted the choice to make the final treatment decision. However, it was also very apparent that most patients needed the clinician to make a treatment recommendation. Thus, decision-making was 'shared' to some extent between the clinician and the patient, but the mutual roles of doctor and patient were not equal, since both participants carried out a different role. The findings from this study support much of the existing research evidence, which indicates that cancer patients do not want a dominant role in the treatment decision-making process. Instead, they favour either a 'shared' role or one which does not require them to make decisions alone (Degner and Sloan, 1992; Fallowfield et al, 1994; Butow et al, 1997; Fallowfield et al, 1997; Rothenbacher et al, 1997). However, according to the current findings, many patients sought the oncologist's recommendation through a prolonged 'negotiation' in order to avoid having to make decisions alone. This finding is new in the sense that it rejects the rather narrow definition of 'shared' decision-making as used in previous investigations, which has focused on whether or not patients want a greater level of participation. In the current study, patients did not participate in the decision-making task in order to make the treatment decision by themselves, or to assert their authority over the decision-making process as found in some previous investigations. Thus, this study demonstrates that the term 'participation' requires re-thinking as it neglects the reasons *why* patients choose to participate in the decision-making task and the actual nature of that participation. Often the *level* of patient participation in decision-making is not an accurate reflection of their real intentions.

One of the reasons why cancer patients delegate decision-making responsibility to the clinician is that the threat of death or recurrence means they are fearful of making the 'wrong' choice (England and Evans, 1992; Sensky and Catalan, 1992; Beisecker et al, 1994; Deber et al, 1996; Johnson et al, 1996; Reaby, 1998). Cancer patients, often those with a worse prognosis, prefer a 'shared' role in decision-making due to the fear that time is too short for gathering information and coming to an independent treatment decision (Meyer et al, 1995; Tabak, 1995).

The decision-making task is not just limited to the clinical setting according to the findings of the current study. Many patients entered into a process of re-evaluation and assessment with their family and friends in an effort to reinforce to themselves that they had made the right decision. Tversky and Kahneman (1974) refer to the 'availability bias' where some patients assess their survival chances by comparing their illness to other people they know who have cancer. In this study, some patients sought the advice of other people with the disease, as a means of reinforcing their sense of optimism. During the observational study, relatives often accompanied the patient to the consultation to act as an additional 'information source'. Thus, patients were able to recall what was said during the consultation via their relative. This provides further evidence that at least some patients actively sought ways of understanding the new situation in which they found

themselves. They often did this through a process of 'evaluation' and 'personal assessment' with friends and relatives.

Information needs

The findings from this study indicated that oncologists found it challenging to translate survival probabilities and risk information in simplified form to patients. Although they summarised the pros and cons of treatment, oncologists were often unable to provide definite assurance that treatment would be 'effective'. Consequently, most patients felt the need to participate in a dialogue with the clinician in order to interpret the information more successfully. A 'negotiation' sometimes took place that sought to resolve some of the uncertainty surrounding the effectiveness of treatment. Thus, information transfer was rarely mono-directional from oncologist to patient. In fact, the patient's input often influenced, and sometimes reversed the oncologist's recommendation.

The findings from this study indicate that the interpretation of information was in many cases assisted by the oncologist, who tailored the information to the individual circumstances and needs of the patient. This assistance with interpretation was highly valued by patients. Contrary to the findings of Charles et al (1998), the role of the oncologist might become more important in future years, especially in helping patients to resolve agonising decisions and by 'filtering' complex concepts. This may require specialist training since clinicians can sometimes overestimate the level of a patient's clinical knowledge and understanding. Patients might not simply find it difficult to understand technical terminology, but also the complex concepts that describe disease behaviour. Clinicians should be trained in divulging specialised information to patients, as this will affect their ability to become involved in the decision-making task.

The large volume of research on patients' information preferences strongly suggests that most patients want full information about their illness and its treatment (Cassileth et al, 1980; Strull et al, 1984; Blanchard et al, 1988; Deber, 1994; Dunsmore and Quine, 1995; Fallowfield et al, 1995; Meredith et al, 1996; Graydon et al, 1997). This suggests that cancer patients do want to play a more commanding part in the communication process with their clinician. However, some studies have shown that although patients are increasingly demanding more information, this demand does not always result in active information seeking by the patient (Beisecker and Beisecker, 1990).

Some clinicians may withhold certain types of information from patients because they may not wish to cause upset, or because they want to increase patient compliance (Eraker et al, 1984).

Other studies have found that the disclosure of information to patients can be affected by the clinician's perception of the patient's emotional stability and intelligence (Rodriguez-Marin et al, 1996). Therefore, it cannot be assumed that clinicians will always communicate information to patients consistently and fully. The information transfer process can be affected by subjective as well as by clinical factors (Miyaji, 1993; Thomsen et al, 1993; Meredith et al, 1996), and there is evidence to suggest that both national and international variations exist in the disclosure of the cancer diagnosis (Thomsen et al, 1993; Blackhall et al, 1995; Rodriguez-Marin et al, 1996; Elwyn et al, 1998). This suggests that doctors often dictate the version of the 'truth' that patients receive. It would be difficult to control the content of the information that the specialist discloses to the cancer patient. However, the standardisation of technical information through the introduction of clinical guidelines is one possible way of achieving some consistency. Although, the problem with this approach is that doctors may feel restricted in their ability to tailor information to the individual circumstances of their patients. Also, standardised information does not account for the fact that some patients may not want to be told all the information, or all the 'truth'. Conversely, more vociferous patients might demand information that the clinician does not possess. Thus, the possibility for controlling the way that doctors communicate technical information is somewhat restricted.

The findings from the current study further indicate that patients did not only want to be told the 'facts' about their illness and treatment, they also wanted to know the 'truth'. Knowing the 'truth' about their condition and treatment enabled them to participate in a 'dialogue' with the clinician, as well as participate in the decision-making task. Patients also sought reassurance from their oncologist as well as from other sources, and this helped them to understand their treatment decision in a more positive light. It is clear from this study that patients did not only want objective 'facts' about survival and treatment benefit for its own sake, they also wanted the information for emotional support. Knowing the 'truth' and being reassured helped many patients to feel positive about the treatment decision which had been reached, and about maintaining a 'fighting' spirit.

Although numerous studies conducted on patients' information needs have indicated that most patients want *more* information (Strull et al, 1984; Blanchard et al, 1988; Deber, 1994; Dunsmore and Quine, 1995; Fallowfield et al, 1995), only a few have specified what *type* of information they require (Luker et al, 1996; Degner et al, 1997; Graydon et al, 1997). The patients in this study primarily sought medical information to help them cope and adjust to their illness, rather than to facilitate their involvement in the decision-making process. This finding contributes to the existing body of research which shows that cancer patients want to be well informed but do not necessarily desire greater involvement in the decision-making process (Sutherland et al, 1989; Degner and Sloan, 1992; Beisecker et al, 1994; Marteau, 1995; Beaver et al, 1996; Fallowfield, 1997).

Continuity of information

Many studies have focused on the information needs of cancer patients during the initial stages of their illness and treatment (Mackillop et al, 1988; Hack, 1994; Hinds et al, 1995; Luker et al, 1996; Degner et al, 1997; Graydon et al, 1997; Vanwersch et al, 1997). However, this study found that patients with colorectal cancer also have a need for more information throughout, and towards the end of their treatment. In other words, they seemed to desire a continuous flow of information. Also, the nature of the information that they require towards the end of treatment can be different to that which they prefer at the beginning. Similarly, they may require different types of information depending on the stage of their disease. Having experienced oncological treatment and its side effects, many patients wanted to know how effective their treatment had been, and what measures they could take to monitor their illness. Indeed, many became more active in their search for information from oncologists, nurses, friends and relatives.

The above findings show that colorectal cancer patients with advanced disease, are better equipped to participate in the decision-making process because they have had more time in which to acquire and process information about their illness, and to assess their future treatment options. They are more able at this stage to assert greater control over their management, and play a more informed role in any future treatment decisions. Although, previous studies have shown that terminally ill patients are more likely to play a more active part in decision-making, they have not considered the longer term information needs of cancer patients. Indeed, many have assumed that it is advanced disease, and the need to 'fight' that disease, which facilitates greater patient participation (Yates et al, 1993; Brown et al, 1994; Downer et al, 1994; McQuellon et al, 1995; Yellen and Cella, 1995). However, the current study is unique in showing that the most important factor that enables patients to participate in the decision-making process might be time from diagnosis rather than disease stage.

'Social Status'

The analysis has shown that although social class had little impact on the decision-making preferences of the informants, their employment and family status did play a part in their treatment decisions. The availability of support from family members was often a key factor in the readiness with which informants accepted the offer of oncological treatment. Since a full course of chemotherapy often takes 6 months, many patients felt that they wanted reassurance

that practical and emotional support was available before they agreed to the treatment. It is evident from the analysis that informants who were living with a spouse or had a close relative to care for them, were more likely to accept the treatment than people who lived alone and had limited support. The availability of practical help such as providing a lift to the treatment centre was often considered to be of great importance by informants in their decision to accept or refuse treatment. Informants who lived alone or had a limited number of relatives were often unable to discuss the treatment decision with anyone except the oncologist. They could only consider their own preferences, and not those of their family, which meant that their treatment choices were often bereft of other peoples' views and opinions. Conversely, informants who had a large network of friends and relatives ready to offer their support usually took those different views into account in the decision-making process. The relative's role was often one that sought to encourage the patient to accept the treatment. Thus, even when patients were reluctant to pursue the offer of treatment, their relatives often reassured them that they should accept it. Patients who lived alone and had limited access to social support tended not to receive the same type of encouragement and reassurance. They could only rationalise the treatment option in terms of their own preference and the oncologist's advice. Moreover, informants sometimes felt compelled to accept treatment because they had young children and grandchildren. To this extent the decision to have treatment was not regarded to be a real choice but a necessity.

The findings fit well with recent studies conducted on the impact of social status on decision-making. For instance, Yellen and Cella (1995) found that having children living in the same dwelling encouraged cancer patients to opt for more aggressive treatment even when the benefit was small. Conversely, patients who had no children living in the same dwelling, and those lived alone, were less likely to accept treatment. This finding supports the findings of the current analysis. Also, Burman and Weinert (1997) found that cancer patients who lived in rural settings were more likely to refuse oncological treatment if they had limited access to transport. Certainly, the issue of treatment convenience and transport was a more salient issue for some patients participating in the current study, and this sometimes played a central role in the patient's treatment decision. In conclusion, oncologists should take into account the level of social and practical support that patients have when deliberating decisions with them, because the patient's decision to accept treatment could be largely influenced by their domestic circumstances and family status.

Age

The study found that patients over the age of seventy found it difficult to act decisively about whether to accept the offer of chemotherapy. Maintaining a good quality of life seemed to be an important issue for 'older patients', which often meant limiting the disruption that a prolonged course of treatment might inflict. 'Younger' patients, who were generally under the age of 65, were more decisive about treatment. In most cases they did not engage in a prolonged deliberation with the oncologist about the pros and cons of chemotherapy because they felt that their only choice was to accept the treatment. However, maintaining a good 'quality of life' in the short term was not as important for informants under the age of 65 who were more prepared to tolerate the adverse side effects of treatment.

The current research on treatment decision-making in cancer indicates that 'older' and less well educated patients do not participate in treatment decision-making to the same extent as 'younger' patients (Pierce, 1993; Thompson et al, 1993; Petrisek et al, 1997). However, most of these studies have been conducted on breast cancer. Therefore, it is perhaps not surprising to find that younger breast cancer patients participate more in the decision-making process considering the large amount of attention that breast cancer has received in the media. It is still not clear though how these studies defined 'decision-making'. The tendency is to accept the view that if there is a high level of patient 'involvement' in the consultation then the patient must be engaged in decision-making. However, if patients are less active in the consultation with the doctor it could be that they have a high level of concordance with the clinician and feel that there is no need for them to engage in decision-making. In some cases, when an important issue arises for the patient, there may be greater motivation to be active in the decision-making process. For example, in the current study quality of life was often an important issue for patients over seventy. In this context, a high level of patient involvement in decision-making can be indicative of an important issue that has arisen for the patient. The study found that 'younger' patients were less active in the decision-making task because issues such as the impact of side effects on quality of life seemed to be less important than they were for 'older' patients. The findings from this study do not support recent research on breast cancer, which suggests that older patients play a limited role in decision-making. Indeed, the current study shows that older patients often played a more active part in deliberations with the doctor than younger patients.

Gender

Most research studies have tended to investigate the role of women with breast cancer in the decision-making process. Therefore, gender differences in cancer treatment decisions have not been considered adequately. The current study found that men and women with bowel cancer differed on the issue of treatment side effects. Women were more concerned about the potential side effects, which could be induced by chemotherapy, especially the possibility of hair loss, nausea, and diarrhoea. Also, they were conscious of the social stigma that could result from having a prolonged treatment course. Men, however, tended to be less concerned about the potential side effects, which they perceived as an inevitable consequence of treatment. One possible explanation for their different responses to the issue of side effects could be that men were more likely to receive a greater level of social and emotional support from relatives who were willing to provide practical help throughout the long course of treatment. Consequently, the issue of debilitating side effects was met with a greater sense of acceptance. Women, on the other hand, may not have expected to receive the same level of support from relatives, and therefore they may have been more conscious of the difficulties that they could experience if they did not receive the same amount of support as men. Existing research suggests that women with breast cancer choose the treatment, which is likely to provide the best chance of cure, and not according to the procedure which will have the most limited impact on body image. This suggests that the physical consequences of surgical treatment options do not usually play a significant part in women's treatment choices. However, only a very limited research literature exists on the impact of chemotherapy side effects on patients' treatment decisions. The current study supports Schover's conclusions that women experience poorer psychological adjustment due to the prolonged nature of the treatment and its impact on physical and social functioning (1995).

Emotions

The research that has hitherto been conducted on treatment decision-making has not considered the impact of emotions. It has generally been the consensus to assume that patients' decisions are often based on calculated and rational thought. The belief that patients make treatment choices on the basis of their emotions such as fear, hope or worry rather than informed judgement, was thought to underestimate their ability to participate in decisions about their own health.

Trust

The findings in the current study showed that most patients trusted the oncologist's judgement, which is why they accepted the treatment recommendation that was provided. This often simplified the decision-making task for the patients who were able to feel secure that the 'best' decision had been made. Not only did informants invest trust in the oncologist, they held clear ideas about what the oncologist had to do in order for this trust to be maintained. Informants claimed that interpersonal factors such as truthfulness, the ability to listen and offer reassurance, were frequently cited as central to the maintenance of trust between the oncologist and the patient. What was also evident from the analysis was that the patient's trust in the oncologist could easily be damaged if the clinician failed to comply with these basic expectations. The trusting bond between the oncologist and the patient was a central factor in a patient's decision to accept the treatment recommendation. Thus, the prerequisite for an acceptable decision was the need to maintain trust in the doctor's judgement. However, the trusting relationship could also be undermined although in most cases it became strengthened as the doctor and the patient developed a closer relationship. Thus, the existence of trust was an essential ingredient within the decision-making process. This does not mean that patients invested blind faith in the doctor's ability to make the right treatment decision. The ability to trust the doctor relieved them of the difficult task of having to make a decision alone. This finding challenges the consumerist suggestion that patients want, and are able to, make their own treatment decisions if they are given all the relevant information. In fact, the current study has shown that many patients with bowel cancer actually prefer to follow the doctor's treatment recommendation, and they are able to do this through the investment of trust in the clinician and his or her clinical expertise.

Fear and hope

The findings from this study strongly indicate that patients did not always want to be told *all* the information about their disease and treatment. In many cases they actively avoided asking certain questions as a means of repressing fear and preserving hope for the future outcome of their illness. In particular, they frequently refrained from inquiring about their prognosis or the likely outcome of their illness in order to avoid worry. More women than men tended to avoid prognostic information, but men also adopted similar strategies in maintaining their optimism. Certainly, the tendency to avoid certain types of information enabled patients to embark on a course of treatment with a greater level of confidence, in the hope that the best was being done to cure their illness. The threat of an uncertain or a 'negative' prognosis could potentially undermine their sense of hope, which is why many patients preferred to avoid such information. Even though the disclosure of a prognosis could enable some patients to make a more informed treatment decision, most patients preferred to avoid such news and accept the treatment in the hope that it would provide a cure. In fact, the avoidance of prognostic information enabled some patients to accept the treatment course with greater optimism.

A relatively small number of patients, all of whom had terminal illness, actually asked the oncologist to provide a prognosis. These patients already knew that they were terminally ill, or at least suspected that they might be, and this made it easier for them to obtain this information from the oncologist. However, they wanted to know how long they had left to live so that they could make plans for the future. For them, the threat that their diagnosis presented could not be avoided because their condition was terminal and they needed to face the likelihood of death. For most other patients who were not in the terminal stages of cancer, they still had the choice to avoid the reality of their illness. This finding shows that patients who are at different stages of their illness may require different types of information about their disease in order to enable them to cope more successfully. Terminally ill patients may prefer to be told their prognosis in order to help them plan their personal affairs more effectively. In contrast, patients with less advanced disease might cope better in the absence of prognostic information.

Practical implications for oncologists

The need to encourage patient involvement in decision-making

The observations identified two types of patient. Firstly, the individual who wanted to resolve the decision-making problem through engaging in a dialogue with the oncologist. Secondly, the patient who played a small part in decision-making and was ultimately prepared to accept the clinician's treatment recommendation. In cases where there did not appear to be a clear treatment benefit, the oncologist summarised the benefits of treatment and finally left the decision to the patient without providing a recommendation. It was in these types of consultations that patients became highly involved in 'negotiating' the treatment decision with the oncologist (see figure 7). However, in cases where the oncologist could provide a treatment recommendation, the patient did not feel a need to become involved in a 'negotiation' to the same extent (see figure 8). Thus, patient involvement in decision-making was often determined by the degree of uncertainty that resulted from the presence or absence of a treatment recommendation.

Figure 7: Decision-making without a treatment recommendation

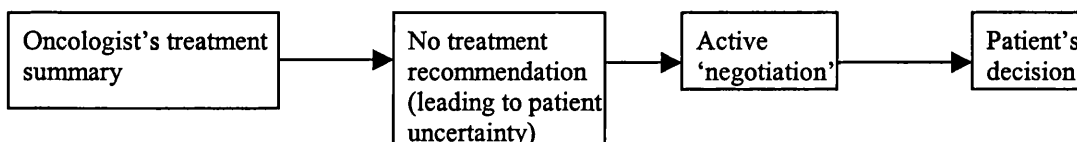
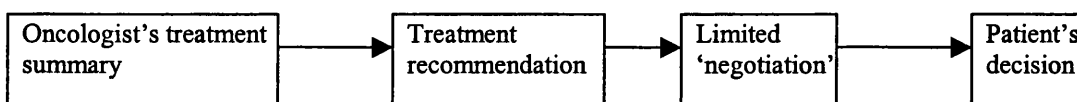


Figure 8: Decision-making with a treatment recommendation



This is similar to the findings of Downer (1994), who found that the clinician was more likely to encourage patient participation when treatment benefit was ambiguous. The decision-making task becomes more difficult in circumstances where the clinician, and not just the patient, is unsure of the best way to proceed. It could be argued that in cases where treatment benefit is uncertain,

patients should be encouraged to play a greater role in the decision-making task so that they are aware of the reasons for the final decision. Therefore oncologist's should encourage patients to ask questions and to take time off to reach their decision. However, there is no simple solution to the decision-making problem in which the doctor cannot provide a treatment recommendation to the patient. In such circumstances, oncologists require the patient's help in reaching an acceptable decision, as much as the patient needs the doctor to provide a recommendation. The greatest difficulty for many patients with cancer is the pressure on them to make up their own mind about treatment when the doctor cannot provide a definite recommendation. The only way forward is through a joint dialogue, although this is a time consuming process which requires constant conjecturing and re-evaluation. Therefore, patients will need open access to relevant sources of information until they reach a decision.

The need to simplify complex information for patients

One of the reasons why patients were experiencing difficulty in making treatment decisions, was that the information communicated to them was difficult to grasp. Patients attempted to overcome their uncertainty by simplifying and summarising the information in a way that made sense to them. However, the problem with this was that sometimes patients could have interpreted the doctor's summary of the evidence in a way that was not clinically 'accurate'. In cases when the oncologist provided a recommendation, patients were usually able to understand the rationale for the decision. In contrast, when a treatment recommendation was not given, patients often drew upon what they perceived the oncologist was recommending or saying. In addition, the fact that patients often interpreted information in terms of a positive outcome for themselves suggests that there was a tendency to be optimistic rather than pessimistic.

The implications for the way oncologists communicate scientific information to patients are significant. Firstly, oncologists are in a powerful position to affect the treatment choices that are made, since a patient's decision is commonly based on the doctor's recommendation. Under these circumstances, oncologists should be cautious not to assume that because patients have accepted their advice, they therefore understand the information that they were given and the reasons why the decision was made. There is a need for oncologists to clarify these issues to patients in simple terms. Secondly, when a treatment recommendation cannot be provided, oncologists should offer to engage in a dialogue with patients in order to help them make a treatment choice. Patients should be encouraged to express their preferences, and helped to explore the advantages and disadvantages of treatment. Certainly, nurses could assist in this task, especially since they may

have a better idea of the patient's social and personal circumstances, which could have a bearing on their decision.

Having a choice is 'no choice'

Many of the patients in the current study perceived the offer of treatment as a necessity rather than an option, and many accepted six months' of highly toxic chemotherapy for little or no benefit. For this reason, oncologists should be aware that patients might often be very eager to accept treatment without fully appreciating its implications. It is, therefore, very important that oncologists fully explain to patients what treatment involves. They should also attempt to elicit their views and preferences, so that they can help them appreciate the advantages and disadvantages of each treatment option. If patients agree to undertake treatment without having adequate information about its consequences, they risk embarking on a long course of treatment with misguided views about its likely benefit. Also, the fact that many patients believed that having treatment would result in a favourable or a positive outcome for them, even when the clinical reality was very different, reinforces the need for oncologist's to disclose information as accurately as possible.

Patients do not want to make decisions alone

The findings of this study also indicate that most patients did not want to make treatment decisions alone, especially when there did not appear to be an optimal treatment choice. As demonstrated earlier, patients often engaged in a 'negotiation' with the oncologist in order to avoid having to make a treatment choice alone. Thus, patients became actively engaged in the decision-making process in order to seek the oncologist's advice about the best way to proceed. It is evident that in cases when patients assumed an active part in the decision-making task, their role was not 'equal' with that of the clinician. Although the patient and the oncologist shared the responsibility for the decision, their respective roles were clearly different. This study shows that the definition of 'shared' decision-making does not imply equality between the doctor and the patient. The patients in the current study often played an active part in decision-making simply to resist having to make a decision alone. Thus, their involvement in the interaction was not a

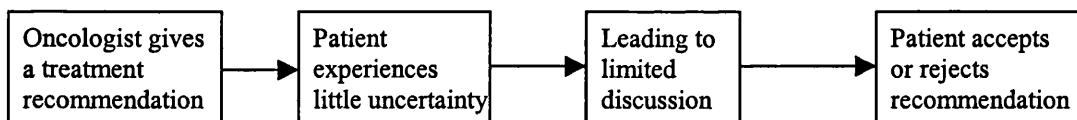
reflection of a 'consumerist' need to assert control over the decision-making process. Their intention was to elicit a recommendation from the oncologist.

Greater patient involvement in the consultation might often indicate that the patient is simply seeking the oncologist's advice about the best treatment option, and not necessarily attempting to dominate the decision-making task. Consequently, it is important for oncologists to assist patients in this process by clarifying the decision-making problem. Even when a clear recommendation cannot be given, patients should still be offered an assessment of the treatment, and encouraged to express their views and preferences. In cases where progress has not been made in reaching an agreed decision, such as when the perceived treatment benefit is uncertain, it is possible that the oncologist has failed to contribute adequately to the decision-making process. By encouraging the patient to think about some of the pros and cons of treatment, and how they might affect his/her social and personal circumstances, the oncologist is more likely to succeed in helping the patient to come to an agreed decision. Figure 9 below provides an illustration of how oncologists might identify the difficulties patients experience in reaching a decision, and help to resolve them.

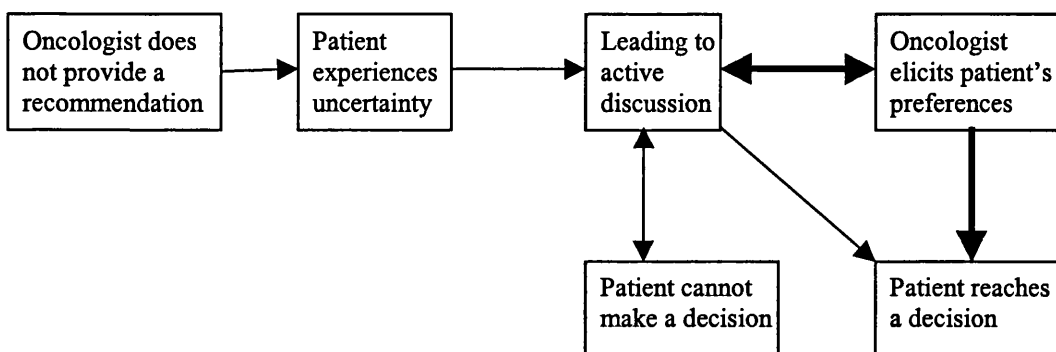
Figure 9: A model illustrating the degree of patient involvement in decision-making

'Preferred' Route ➡
'Typical' Route ➡

Level of patient participation (with a treatment recommendation)



Level of patient participation (without a treatment recommendation)



Communicating the ‘truth’

Oncologists are confronted with a paradox. On the one hand, they are required to provide the ‘truth’ to patients, and on the other hand they are unsure about what level of truth is the optimum to divulge. Indeed, probabilistic information can be expressed in both ‘negative’ and ‘positive’ terms depending on whether mortality or survival information is emphasised. So, clinicians can inadvertently give the impression that one treatment option is favourable over another. Moreover, oncologists have the ability to control what they choose to disclose to patients. Deciding to withhold certain types of information could be viewed as concealment or the manipulation of the facts. However, certain facts could also be damaging to patients, and some might not want to be told everything. Nevertheless, most of the patients in this study did want the doctor to provide some form of a treatment recommendation. So, although the provision of the whole ‘truth’ might be difficult to achieve, clinicians should provide an assessment of the information that will enable patients to work with them towards a decision.

Some policy implications of the findings

This study has shown that the process of categorising technical information is not only a ‘cognitive’ activity it is also influenced by the involvement and input of the clinician. Indeed, the process of interpretation often involves a mutual exchange or a ‘negotiation’ between the doctor and the patient. It is in this way that the patient is able to simplify probabilistic information by interpreting it categorically. This finding has several implications for the patient’s role in the decision-making process and for the future structure of cancer care.

The finding that patients are often guided by clinicians in the decision-making process, is very different to that reported by Charles et al (1998) who found that patients make sense of clinical information largely without the doctor’s guidance. The finding by Charles et al (1998) implies that patients play a greater part in the task of interpreting information as well as in assessing the pros and cons of treatment. This suggests that they possess the ability to make sense of complex information without the oncologist’s guidance and interpretation. Certainly, some studies have shown that cancer patients often maintain a positive outlook in the face of conflicting information (Mackillop, 1988; Weeks et al, 1998), which suggests that they can cast their own opinion on certain facts, or that they tend to misrepresent the information that is communicated to them. The current study indicates that although patients simplify the information that is disclosed to them,

the process through which they do this is more complex than suggested by Charles et al (1998). If information is largely interpreted by the clinician for the patient, then this means that the decision-making power still rests with the clinician. Indeed, many patients in the current study preferred the oncologist to assume the decision-making responsibility and to provide a treatment recommendation.

The increasing salience given to evidence-based decision-making implies that treatment decisions will be increasingly guided by evidence from clinical studies. This means that clinicians may face a continuous challenge in communicating research evidence to patients. As a result, clinicians could face increasing demands from their patients, not only for more information, but also for an interpretation of the evidence. The consequence of such a policy might be that consultations will require more time, or clinicians will be less willing to disclose all the 'facts' on the premise that clinical evidence is too complex and confusing for patients. Thus, the practice of evidence-based medicine may begin to extend the boundaries of the information. The greater emphasis on site-specialisation and on more effective utilisation of specialist expertise in cancer care, is another signal that the management of cancer is geared towards a greater use of research evidence in decision-making. The danger being that if cancer management becomes over-dependent on evidence-based medicine, then the role of the patient in making decisions about their own treatment could be restricted.

As the findings of this study indicate that patients prefer the oncologist to play a dominant role in decision-making, there is likely to be an expectation that clinicians *can* and *will* provide the 'answer' to the decision-making dilemma. The issue of whether or not evidence-based decision-making affects the doctor's ability to communicate effectively with patients could not be fully addressed in this study. However, there is need for further research to examine the most effective way of communicating research based information to patients. The findings from this study suggest that because patients aim to maintain a positive outlook, they may not desire detailed information about the pros and cons of treatment so much as positive reinforcement from the oncologist. This question still needs to be explored further by subsequent research.

This study also found that family and friends often played an important part in the decision-making process, especially in the task of helping patients evaluate the information disclosed by the clinician. This indicates the need for cancer specialists to involve members of the patient's family within the doctor-patient interaction. Oncologists should also consider what has been discussed within the family beyond the realm of the clinic.

Most patients in this study felt that they did not have a valid treatment choice because they felt that the offer of treatment was too risky to refuse. This finding suggests that cancer patients are willing to undergo highly toxic treatment because they feel that the risk of recurrence is too great (Yates et al, 1993; Brown et al, 1994; McQuellon et al, 1995; Yellen and Cella, 1995). One implication of this finding is that the demand for post-surgical cancer therapy could be set to rise.

However, such escalation could also be a reflection of the referral patterns of surgeons to some extent. This is because many patients expect to be offered treatment simply because they have been referred to an oncologist. Thus, the demand for treatment by cancer patients might be the product of referral, rather than an accurate indication that all cancer patients demand cancer treatment. Further research is required to explore this issue further.

Recent developments in cancer care

Cost shifting

The treatment decision-making process between the cancer specialist and the patient is often influenced by wider health policy at the local and national level. Studies that have investigated the treatment decision-making process in cancer have seldom drawn a link with the context in which decisions are made. For instance, the fact that certain treatment options are available to patients in one region of the country and not in another has not been considered. Also, the issue of why patients, attending certain hospitals have access to a palliative care team and others do not, has been neglected in the context of decision-making. The organisational changes that have been recommended by the Calman-Hine Report (1995) coincided with the current study. Therefore, it was important to consider the implications of this report for the changing organisational context of cancer care. The changes implemented by Calman-Hine were an attempt to reorganise and centralise cancer services with a view to delivering cost-effective care that would be more responsive to patient needs.

Patient demand on cancer care has increased in recent years, and the resulting cost pressures on specialist centres such as the Bristol Oncology Centre have been particularly intense over the past five years. The findings from this study suggest that one way in which some consultants have responded to pressures of increasing workload, is through the earlier discharge of patients. This means that patients who have completed their treatment at the oncology centre, are often referred back to the care of their GP and surgeon. Indeed, Avon Health Authority, as well as many other health authorities, are actively encouraging the earlier discharge of patients. Their rationale for such action seems to be that the greater involvement of GPs in the care of cancer patients will improve communication channels between the specialist, the GP, and the patient.

As patients become discharged earlier from hospital, the cost and the burden of care will be shifted to primary care teams, and the responsibility for follow-up of patients will be increasingly

placed in the hands of GPs. However, there is reason to believe that many GPs may not possess the necessary expertise to provide adequate follow-up care, nor sufficient knowledge to ensure that patients receive the information and advice that they require (Grunfeld et al (1995). This is particularly important as the results of this study indicate that patients want to be closely informed of their progress throughout the course of their illness, and to receive information on a continuous basis. Also, studies have shown that post treatment screening is very successful in improving the survival rate (Bergamaschi and Arnaud, 1996). For this reason it is very important that follow-up management is effective. Thus, the shifting of follow-up care to the primary care sector should be carefully evaluated to avoid shortfalls resulting from early discharge.

The referral patterns of GPs and surgeons could also increase demand on expensive cancer therapy. This is because many patients assume that a referral necessarily implies they will be treated. Also, this study has shown that patients with colorectal cancer who are referred to the oncology centre are likely to accept the treatment that they are offered. In addition, the analysis in this study has indicated that patients who are referred to an oncology centre tend to present with more challenging conditions, and this could further contribute to escalating treatment costs as referrals increase.

Contracting

The Calman-Hine (1995) recommendations suggested that contracting for cancer services should be based on individual cancer sites to improve accountability and the effective use of resources. Thus, resources will be provided according to the requirements of the individual oncological sub-specialities. Currently, at the Bristol Oncology Centre the annual budget is re-distributed internally to cover all the services that are provided. Therefore, an emphasis on contracts that are sensitive to each cancer site may restrict the flow of revenue between individual services (Whitehouse, 1995). Alternatively, such a policy may neglect the additional costs of cancer care that are not always given adequate recognition, such as long-term, informal, and nursing care. Also, an element of competition could be introduced between the different sub-specialities responsible for individual cancer sites, whereby oncologists may need to demonstrate more forcefully why they need greater funds than other specialities. The likely outcome of a contracting policy that does not allow for sufficient flexibility in the way that services are delivered and how the money is spent is that there will be greater financial pressure.

The emphasis on the greater cost-effective use of resources by purchasers could also drastically affect the delivery of cancer care and the treatment decision-making process. Providers

increasingly need to demonstrate the cost-effectiveness of services to purchasers in order to secure future funding. The interviews with oncologists at Bristol Oncology Centre have indicated that cancer services are being subjected to tighter checks to ensure an effective use of resources. Oncologists have started to offer less palliative chemotherapy to patients due to its limited ability to increase survival and other outcomes. This means that in the future, palliative chemotherapy may have a lower priority than other cancer treatments that are offered to patients. The case of Helen Bourton indicates that even certain chemotherapy regimens, which are considered to be clinically effective, may be placed lower down the list of priorities. Alternatively, they may be withdrawn purely on grounds of cost. Therefore, the issue for treatment decisions is not only what patients and physicians decide, but also what treatments are offered to patients in the first place. Obviously, the decision-making process is very much affected by the types of therapies that are made available for patients to decide upon.

Certainly, initiatives to scale down the number of patients who receive palliative chemotherapy at Bristol Oncology Centre could be perceived as an attempt to limit certain services and patient throughput. Indeed, the findings of this study have shown that certain patients with colorectal cancer are 'encouraged' to decline chemotherapy treatment due to its limited 'benefit'. Thus, the move towards a more cost-effective use of resources could limit the treatment options that are on offer to patients. However, there is a glimmer of hope in the longer-term contracting relationships that providers and purchasers are starting to forge. Although purchasers are exerting pressure on providers to cut down costs, many are also establishing long-term plans with providers via longer-term contracting (Redmayne, 1996). This way annual targets achieved by providers can be assessed within the context of longer-term strategies. Also, the decision whether to offer certain drugs to patients will be made in a joint effort between providers and health authorities. This will in turn introduce greater long-term stability into the contracting process.

The treatment decision-making task is made more complicated when the additional ingredient of 'quality of care' is entered into the equation. The issue of 'equity' and 'appropriateness' in the delivery of cancer services has attracted much public attention in recent years. The way in which purchasers, clinicians, and indeed the public, define a 'good quality' service, will have direct implications for the way that services are delivered. The definition of what constitutes a 'good' service from the purchaser's perspective may sometimes conflict with that of the clinician and the patient. Consequently, the needs of the entire population may come before that of the individual patient. The results from this study show that purchasers are increasingly faced with difficult choices that often defy a simple solution.

Establishing greater equity or tighter control over priorities?

Control over the decision-making process is largely held by clinicians who have sole responsibility for the allocation of resources through their treatment decisions. Increasingly though, purchasers have started to play a greater role in allocative decisions by demanding greater accountability from providers, and through establishing longer-term contracts for strategic planning of services. The issue of equitable cancer care provision has been raised in the media recently with reference to the Helen Bourton case. This highlights the tensions, which exist between population and individual choice with regards to cancer treatment. Avon Health Authority has been arguing that although there is regional variation in the delivery of cancer services, the overall quality of cancer care in Bristol is high. For instance, the supportive services which are provided alongside the multidisciplinary structure within which treatment is offered, means that the emphasis in Bristol is on the overall 'package' of care. Indeed, the analysis has shown that Avon Health Authority aims to establish an equitable service. Thus, in Bristol the requirements of the population overshadow those of the individual to some degree.

Avon Health is trying to limit clinical discretion in treatment decision-making to some extent, so that certain patients do not receive a preferential service over other patients. For this reason cancer care in Bristol is allocated to ensure that all 'deserving' cases receive an equal service. For this reason, Avon Health is starting to become more explicit in its allocative decisions, so that patients are more aware of what to expect in terms of care. Setting quality standards in care will be achieved through comparing cancer with other conditions, and also by establishing national guidelines for cancer services.

Most health authorities possess mortality and morbidity data for their local populations, but this is often insufficient to identify specific health care needs. Thus, a better way of measuring 'need' is even more necessary for planning health services, at a time when greater demands are being made on NHS resources. The decision made by Avon Health Authority about withdrawing Taxol from its list of priorities show that data on 'appropriateness', patient 'need', or 'clinical effectiveness' cannot by themselves determine whether a certain service will be made available to patients. Just because a service has been shown to be effective or appropriate, does not mean that it will be made available. Evidence on whether it serves the population as well as it does the individual, will increasingly need to be demonstrated.

The greater emphasis on the use of clinical guidelines in cancer care also suggests that Avon Health Authority is encouraging clinicians to exert tighter control over the use of resources. However, some oncologists at Bristol Oncology Centre have indicated that clinicians still need to

exercise some flexibility when making decisions. Therefore, although Avon Health will determine the level of revenue allocated to certain services, the decision whether to offer a service to a patient will still be made by the individual clinician. Some have suggested that decisions about which services are given higher priorities, are often disguised as clinical decision-making (Klein et al, 1996). Thus, clinicians make treatment decisions within the financial constraints that they face. This pattern of allocating resources is apparent in Bristol Oncology Centre where palliative chemotherapy is being given lower priority, and oncologists are increasingly deciding who should receive it on the basis of cost, as well as clinical need.

Conclusion

In conclusion, this study has identified some of the complexities surrounding treatment decision-making in colorectal cancer. The way that patients interpret the information that they are given can have important implications for their treatment preferences. Indeed, this process of interpretation is often aided by the clinician who provides a summary of the information, followed by a treatment recommendation. The patients who participated in this study expressed a need for advice and guidance from their treating clinician, in order to help them understand the treatment decision and the complex information. Often patients felt that they did not have a choice regarding treatment since undergoing further therapy offered them a sense of hope and optimism about the future, and a feeling that they were maintaining their fight against cancer.

The study also found that patients usually preferred a 'shared' approach to decision-making in order to absolve themselves from total responsibility for the outcome of their illness. They also opted to discuss the treatment options with their family and friends as reassurance that they had made the best possible decision. These findings could have implications for clinical practice. For example, patients might benefit from strategies to improve the way in which treatment options are presented, and the type of support offered in making their treatment decisions.

The move towards greater specialisation and centralisation in cancer care could lead to an 'expert' led service. However, this may not necessarily indicate that the quality of care will improve, especially because the Calman-Hine recommendations were specifically aimed at reorganising existing services, without any additional revenue. This means that there is the possibility that cost pressures may be shifted to primary and community-care teams. This policy alongside the increasing emphasis on cost-effectiveness could result with patients being denied certain treatments including chemotherapy. As costs rise, the pressure on purchasers to assign lower priority to certain treatments will also increase. Consequently, the commitment by some

health authorities to place the needs of the population before those of the individual patient will inevitably lead to stricter controls on spending. Whether this trend will lead to more equitable cancer services is debatable, and how such a policy will influence the patient's role in treatment decision-making is yet to be seen. However, there are signs that increasing cost pressures will have a direct impact on the types of treatments that are offered to cancer patients and also on the way that doctors and patients negotiate treatment decisions.

APPENDICES

Appendix 1

Patient Information Sheet

Treatment decision-making: the role of patients, relatives, and health care professionals

Introduction

You may remember me from when you last attended the Bristol Oncology Centre when I was accompanying Dr... in the clinic. I am a research student in the Department of Social Medicine, University of Bristol, and I am writing to you to ask whether you would be prepared to discuss certain aspects of your treatment with me. This research project is about patient satisfaction and involvement with treatment plans, and hopes to identify ways in which oncology services can be improved.

I would like to come and talk over your feelings regarding the treatment choices that were offered to you sometime next week, and again in four months' time. I would be happy to come to see you in your home at any time that is most convenient to you.

Purpose of the study

The purpose of this study is to explore the ways in which treatment decisions are made between oncologists, nurses and patients. One of the factors that enable people to take part in treatment decision-making is a good supply of information and a good understanding of the proposed treatment. This study will look at the ideas people have formed from their experience of medical care.

Benefits of the study

The main aim of the study is to investigate your experiences and perceptions of care at the oncology centre, which will hopefully lead to a better understanding, and ultimately to an improvement in service provision. The study will draw attention to your information needs and your satisfaction with the service that you received at the oncology centre, which will hopefully lead to improved health care for future patients. It is anticipated that this study will provide you with an opportunity to voice your views and discuss issues which are most important to you, and which will serve to provide us with a better idea of the type of health care patients attending the oncology centre may want in the future.

What the study involves

The discussion will take place between me and you in your own home (or where you choose), and will cover issues that you consider to be most important. The discussion is intended to be informal, and can be stopped or postponed at your convenience. It is hoped that you will be able to take part in one more discussion which will take place four months after the initial one, in order to discuss your views about the care that you have received up to that point. In addition, your surgeon will be contacted prior to your transfer to the oncology centre.

Confidentiality

Any information that you disclose during the discussion will be strictly confidential, and it will only be used by myself for the study. You may decline to participate in this study or withdraw at any point from the study without giving a reason. Information which you provide to me will be kept in such a way that you cannot be identified, *and nothing that you say during the interviews will be disclosed to your doctor.*

Further information

I would be very happy to provide you with further information about this study if you should so wish. If you would like to get in touch with me for an informal chat please telephone **Bristol 928 7278.**

Could you please complete the tear-off slip below and send it back to me in the enclosed paid envelope (you do not need to pay the postage). I would be grateful if you could do this as soon as you can. Once again, I would like to assure you that anything we discuss will be entirely confidential and is completely unconnected to any aspects of your health care.

Thank you for considering to help me with this study. I look forward to hearing from you soon.

Yours sincerely,
Tom Sanders
(Research Student)

✕-----
(Please tick a box)

1. Yes, I am willing to participate in the study. ☐
2. Yes, I may be willing to participate in the study,
And would like more information first. ☐
3. No, I am not willing to participate inn the study. ☐

Could you write your address and telephone number here please:

Your name and address:

Your telephone number:

----- postcode -----

Appendix 2

Coding Frame

1 First Impressions of Oncology Centre

- 1.1 expectations of oncology centre
- 1.2 impressions of clinic
- 1.3 previous experience of oncology centre
- 1.4 expectations of side effects

2 Relationship with Medical Staff

- 2.1 expectations of doctor
- 2.2 expectations of nurses role
- 2.3 frequency of contact with doctor
- 2.4 recognition of medical skill
- 2.5 relationship with staff
- 2.6 role of nurses
- 2.7 trust in doctor
- 2.8 talking with nurses
- 2.9 perception of doctor
- 2.10 frequency of contact with nurses
- 2.11 satisfaction with nurses
- 2.12 relationship with nurses
- 2.13 role of dietician
- 2.14 satisfaction with doctor
- 2.15 role of doctor
- 2.16 reason for seeing doctor
- 2.17 satisfaction with doctor contact
- 2.18 content of consultation
- 2.19 relationship with doctor
- 2.20 doubts about medical skill

3 The uses of information

- 3.1 understanding differences between chemotherapy and radiotherapy
- 3.2 disclosure of diagnosis
- 3.3 information disclosed by doctor
- 3.4 information provided by nurses
- 3.5 nature of information
- 3.6 problems with recall of information
- 3.7 provision of information
- 3.8 satisfaction with information
- 3.9 the need for information
- 3.10 ability to recall information
- 3.11 understanding treatment
- 3.12 unexpected information
- 3.13 interpretation of information
- 3.14 use of medical terminology
- 3.15 conflicting information
- 3.16 use of information centre
- 3.17 understanding the illness

- 3.18 understanding the information provided
- 3.19 not understanding treatment
- 3.20 inaccurate information provided
- 3.21 amount of information required
- 3.22 advice of doctor
- 3.23 reading newspapers
- 3.24 rejecting doctor's advice
- 3.25 other sources of information
- 3.26 volume of information given

4 The role of Uncertainty

- 4.1 the need for certainty
- 4.2 uncertainty of patient
- 4.3 uncertainty of outcome
- 4.4 doctor's uncertainty
- 4.5 uncertainty of test result

5 Reactions to Treatment

- 5.1 allocation of treatment
- 5.2 dissatisfaction with treatment
- 5.3 duration of treatment
- 5.4 expectations of treatment
- 5.5 experimental nature of treatment
- 5.6 interference of treatment
- 5.7 preventative nature of treatment
- 5.8 satisfaction with treatment process
- 5.9 preparations before surgery
- 5.10 perceived benefit of treatment
- 5.11 administration of treatment
- 5.12 acceptance of treatment
- 5.13 stage of treatment
- 5.14 recovery from surgery
- 5.15 post treatment monitoring
- 5.16 novel treatments

6 Decision making

- 6.1 patient decision-making role
- 6.2 satisfaction with decision
- 6.3 patient's expectations of decision making
- 6.4 understanding the decision
- 6.5 discussing treatment with relatives
- 6.6 the need for rationality
- 6.7 the role of feelings
- 6.8 refusal of treatment

7 Choice

- 7.1 degree of choice
- 7.2 the need to provide choice
- 7.3 treatment choice
- 7.4 explanation of choice by doctor
- 7.5 provision of choice

7.6 no choice

8 Side Effects

8.1 reaction to side effects

8.2 understanding the side effects

8.3 side effects experienced

8.4 use of medication for side effects

8.5 satisfaction with medication

8.6 managing side effects

9 Organisational Factors

9.1 between-firm comparison

9.2 efficiency of staff

9.3 x-ray process

9.4 organisation of care

9.5 dissatisfaction with organisation

9.6 waiting time

10 Hospital Distance

10.1 distance to hospital

10.2 means of transport

11 GP's Role

11.1 GP's Advice

11.2 reason for presentation to the GP

11.3 GP's role

12 Coping Strategies

12.1 coping with colostomy

12.2 coping with diagnosis

12.3 emotional reactions

12.4 hope

12.5 recognition of patient rights

12.6 thoughts about future

12.7 reversal of colostomy

12.8 coping with illness

12.9 coping with treatment

12.10 keeping a positive attitude

12.11 coping with home life

13 Role of Family and Friends

13.1 others' reaction to patient

13.2 reassurance from others

13.3 role of spouse

13.4 advice from others

13.5 help received from others

13.6 satisfaction with support

14 Patient's Role

14.1 responsibility of patient

15 Referral Process

15.1 pathway to the hospital

15.2 delay in referral

15.3 speed of referral

16 ‘Quasar’ Trial

16.1 Framing information by doctor

16.2 Persuasion by doctor

16.3 understanding the Qasar trial

17 Communication

17.1 Satisfaction with Communication

17.2 Style of Communication

17.3 Inadequate communication

18 Question Asking

18.1 asking about diet

18.2 asking about treatment

18.3 asking about the disease

18.4 asking about using facilities

18.5 asking nurses for advice

18.6 asking questions of doctors

18.7 asking questions of nurses

19 Responses to Illness

19.1 present state of health

19.2 previous experience of cancer

19.3 experiencing pain

19.4 taking control of the illness

19.5 signs of improvement

19.6 anticipating the worst

20 Alternatives

20.1 impressions of CHC

20.2 type of therapy

20.3 frequency of visits

20.4 perception of staff

20.5 information provided at CHC

20.6 seeing the pharmacist

20.7 pharmacist’s advice

20.8 considering private treatment

20.9 impressions of cancer support group

21 Presentation of Risk

21.1 possibility of recurrence

22 Ethics

22.1 given the option to refuse entry into trial

Appendix 3

Outpatient Clinic Observations

Name of patient

Age

Clinic date and time

Doctor

Family Present

Non-family present

Length of consultation

Diagnosis (given?)

Outcome of consultation

Discharge or referral elsewhere

out-patient follow-up

Chemo/radiotherapy

No decision

Did doctor invite questions

No

Yes

Location of examination

desk

couch

side-room

Decisions:

a) Medical preference stated (yes/no)

b) Medical intention stated (yes/no)

- c) Family assent requested (yes/no)
- d) Family allowed to make decision (yes/no)
- e) Family dissent from doctor's proposal (yes/no)

Uncertainty expressed by Dr:

- a) over diagnosis
- b) over treatment

Extent of jargon used by doctor

Description of Clinic Setting:

- a) Theme of the consultation:
- b) Topics discussed (in detail):
- c) Manner of the participants (doctor, patient, family, nurse):
- d) How were decisions reached? The role of the doctor and patient/family:
- e) Extent/nature of patient involvement in decision making:
- f) Type of doctor-patient interaction (refer to the models):
- g) Describe the involvement of family members present:
- h) Any other observations:

Appendix 4

Interview Guide

Preamble:

Thank you very much for letting me come to talk to you about your experiences in the oncology centre. As I explained in my letter to you, this study is about improving patient services and what I would like to do today is to ask you a few questions about what you feel is important about the care you received from the hospital. First, though, I would like to explain a little about this interview.

1. First, nothing of what you say will be told to your doctors in a way which would identify you. I am talking to a lot of other people like yourself, and I will write a report for the doctors at the end of the study. This report will summarise what you and others say so that doctors can understand your feelings and concerns, but nobody will be identified personally.
2. Second, I would like to tape-record our conversation if you have no objections to this. This will save me from making notes and possibly missing some of what you have to say. However, we don't have to use the tape recorder if you feel strongly about this.
3. Third, you don't have to answer any of the questions if you don't want to, and we can finish the interview at any time you wish.
4. Do you have any questions before we turn on the tape-recorder and start the interview?
- 5.

Decision-making

1. Did you have any experience of the Oncology Centre before you attended there last month (time scale as appropriate)?
2. How did it strike you when you attended there?
3. What did you think about the care you received in the Oncology Centre?
 - What did you expect was going to happen?
 - Did it happen like that?
4. How did you get along with the doctors who were involved in your care?
 - When you came to the Oncology Centre what did the doctor tell you?
 - Was there anything you wanted to know from the doctors which wasn't explained to you (either verbally or in written form)?
5. Was anybody else (or organisation) involved in your care whom we haven't talked about, who was important in understanding your illness and your treatment?
6. How involved did you (and do you) feel in the plans made for your illness and treatment?
 - Do you think this could be changed in any way?

- Did you help to decide what treatment you were going to have?
- If not, do you think you would have liked to take part in deciding on the treatment?

7. Were you asked to take part in a clinical trial at the Oncology Centre ('Quasar')?
 - Tell me your views about being asked to participate?
 - Did you agree to take part in the trial?
 - What do you understand about the trial?
 - Do you feel you understood enough?
 - Who explained to you the purpose of the trial?

Information Preferences

8. Did members of your family or friends play a role in helping you decide to see the doctor?
 - What sorts of things did you discuss with them?
 - Were they helpful to you?
9. How did you first come to see your GP?
 - Were your family involved in helping you decide?
10. What happened when you saw your GP for the first time?
 - What did you understand from what he/she told you?
 - Did the doctor tell you everything you wanted to know?
 - Would you have liked to been told anything else by your GP?
11. At your first appointment at the hospital (before surgery) what sorts of things did you discuss with the doctor?
 - Were you happy about the information you were given by your doctor?
 - Looking back, is there anything you would like to have been told by the doctor but were not told at the time?
 - How do you feel about having undergone the operation?
 - Did you understand your doctor at the Oncology Centre?
12. What are your expectations about the care which you would like to receive here?
 - Do you have any anxieties?
 - Have you felt any uncertainty about your proposed treatment plan?
 - If yes, how have you attempted to overcome your uncertainty?
13. Have your family (or friends) come along with you to your appointments?
 - How much have you been able to discuss your illness and treatment with your family and friends?
14. How did you get along with the nurses who were involved in your care?
 - Was there anything you wanted to know from the nurses which wasn't explained to you (either verbally or in writing)?
 - How helpful did you think the nurses were to you?

Psychosocial Factors:

15. How would you say you feel about yourself at the moment?
-How did your family or relations help you to cope lately?
16. How has your recent treatment affected your life at home?
-Do you feel you're getting enough support to carry out everyday tasks?
-How has your health been since the operation?
-Do you experience any physical problem?
17. What thoughts do you have about undergoing treatment at the Oncology Centre?

General:

18. Thinking about your own experiences in the Oncology Centre, is there anything you would like to change to make the experience better for other people in the same position as yourself, coming to the Oncology Centre for the first time?
19. Is there anything which we haven't talked about which you think is important for other people in a similar position as yourself, and which you think might improve the care that people receive?

Appendix 5

Matrix

Both tables below demonstrate how certain themes could be mapped in order to provide a visual representation of the data. The first table demonstrates how informants who had accepted treatment understood the severity of their illness. Most informants claimed that they accepted treatment due to five broad issues/reasons which were: survival issues, the doctor's recommendation, disease related factors, treatment related issues, and domestic concerns. The 'definition' column provides further detail about what the five issues involved. For instance, when informants stated that they felt domestic issues played a central role in their decision, these were because the family placed pressure on the informants to accept treatment or that they were having treatment for their family. In addition, the top row provides common responses regarding the extent to which informants felt that their illness was 'serious' or 'less serious'. The responses ranged from 'not advanced' to 'life threatening'. All the responses were placed in the appropriate grid in the table, where a clustering of responses can be identified. Using this grid or matrix, it is evident that most respondents believed that their cancer was 'malignant', and their reasons for accepting treatment varied across all five response categories. The second matrix provides a similar description of the reasons why the interview respondents rejected the treatment. This method of visually representing the data proved fruitful in illustrating patterns in the data.

Reason for accepting/rejecting decision by ‘understanding the illness’

Why accepted	Definition	LESS SERIOUS ILLNESS				SERIOUS ILLNESS		
		Not advanced	Not spread	Curable/ cured	Uncertain of spread	Malignant	Not curable	Life threatening
Survival reasons	1. To extend life				A	A A A A P P P P P	P P P	A P P P P
Doctor’s advice	1. Guided by doctor 2. Doc said he had to have it			A	A A A	A A A P A		P
Disease related reasons	1. May be too weak to have it later 2. To get rid of tumour			A A	A	P P A A	P P	P P

LESS SERIOUS ILLNESS

SERIOUS ILLNESS

Why Rejected	Definition	Not advanced	Not spread	Curable/ cured	Uncertain of spread	Malignant	Not curable	Life threatening
Disease related reasons	1. Cancer was too advanced					P P		P P
Doctor's advice	1. He could not argue with doctor 2. He wouldn't advise it			A	A	P		P A
Treatment related	1. Treatment would have no/limited benefit 2. Side effects too harsh			A A	A A A A	P P P	P	P P A P A P
Life related	1. Need to get on with the rest of life 2. Too old			A	A A A			A

A=Adjuvant Chemotherapy

P=Palliative Chemotherapy

Bibliography

Abramovitch,H; Schwartz,E (1996): Three stages of medical dialogue. *Theoretical Medicine* 17, 175-187.

Adamson,C (1997): Existential and clinical uncertainty in the medical encounter: an idiographic account of an illness trajectory defined by Inflammatory bowel disease and vascular necrosis. *Sociology of Health and Illness* 19 No.2, 133-159.

Allender,E (1973): Diagnostic process and rheumatic disease. *Scan.J.Soc.Med* 1, 97-108.

Anderson,H; Palmer,MK (1998): Measuring quality of life: impact of chemotherapy for advanced colorectal cancer. Experience from two recent large phase III trials. *British Journal of Cancer* 77 (Supplement 2), 9-14.

Arnason,V (1994): Towards authentic conversations. Authenticity in the patient-professional relationship. *Theoretical Medicine* 15, 227-242.

Ashby,J; Buxton,M; Gravelle,H (1990): Will a breast screening programme change the workload and referral practice of general practitioners? *Journal of Epidemiology and Community Health* 44, 36-38.

Ashcroft,JJ; Leinster,SJ; Slade,PD (1985): Breast cancer-patient choice of treatment: preliminary communication. *Journal of the Royal Society of Medicine* 78, 43-46.

Audisio,RA; Filiberti,A; Geraghty,JG; Andreoni,B (1997): Personalised surgery for rectal tumours: The patient's opinion counts. *Support Care Cancer* 5, 17-21.

Ball,JK; Elixhauser,A (1996): Treatment differences between blacks and whites with colorectal cancer. *Med.Care* 34 No.9, 970-984.

Barr,D (1990): Competent patients and irrational choices. *N.Eng.J.Med* 323 No.19, 1353-1354.

Barsevick,AM; Pasacreta,J; Orsi,A (1995): Psychological distress and functional dependency in colorectal cancer patients. *Cancer.Practice*. 3 No.2, 105-110.

Baum,F (1995): Researching Public Health: Behind the Qualitative-Quantitative Methodological Debate. *Soc.Sci.Med.* 40 No4, 459-468.

Beaver,K; Owens,RG; Leinster,SJ; Degner,LF; Sloan,JA (1996): Treatment decision making in women newly diagnosed with breast cancer. *Cancer.Nurs.* 19 No1, 8-19.

Beck,Robert,J; Scardino,Peter,T (1994): How useful are models of natural history in clinical decision making and clinical research? *Journal of clinical epidemiology* 47 No1, 1-2.

Becker,HS (1984): Problems of inference and proof in participant observation. In: *Qualitative Methodology: Firsthand Involvement with the Social World*. 1st ed. Vol. 1. (Ed: Filstead,WJ) Markham Publishing Company, Chicago, 189-201.

Becker,HS; Geer,B (1970): Participant observation and interviewing: a comparison. In: *Qualitative Methodology: Firsthand Involvement with the Social World*. 1st ed. Vol. 1. (Ed: Filstead,WJ) Markham Publishing Company, Chicago, 133-142.

Becker,HS; Geer,B (1984): Participant observation: the analysis of qualitative field data. In: *Field Research*. 1st ed. Vol. 1. (Ed: Burgess,RG) George Allen and Unwin, Boston, 239-249.

Beisecker,AE; Helmig,L; Graham,D; Moore,WP (1994): Attitudes of oncologists, oncology nurses, and patients from a Woman's clinic regarding medical decision making for older and younger breast cancer patients. *The Gerontologist* 34 No4, 505-512.

Beisecker,AE; Beisecker,TD (1990): Patient information-seeking behaviours when communicating with doctors. *Med.Care* 28 No1, 19-28.

Bekkers,MJTM; Vanknippenberg,FCE; Vandulmen,AM; Vandenborne,HW; Vanbergehenegouen,GP (1997): Survival and psychosocial adjustment to stoma surgery and nonstoma bowel resection: a 4-year follow-up. *Journal of Psychosomatic Research* 42 No.3, 235-244.

Bennett,FJ (1995): Qualitative and quantitative methods: in-depth or rapid assessment. *Soc.Sci.Med.* 40 No12, 1589-1590.

Benson,J; Britten,N (1996): Respecting the autonomy of cancer patients when talking with their families: qualitative analysis of semistructured interviews with patients. *BMJ* 313, 729-731.

Bergamaschi,R; Arnaud,JP (1996): Routine compared with nonscheduled follow-up of patients with curative surgery for colorectal cancer. *Annals of Surgical Oncology* 3 No.5, 464-469.

Biley,F (1992): Some determinants that effect patient participation in decision-making about nursing care. *Journal of Advanced Nursing* 17, 414-421.

Blackhall,LJ; Murphy,ST; Frank,G; Michel,V; Azen,S (1995): Ethnicity and attitudes towards patient autonomy. *Journal of the American Medical Association* 274, 820-825.

Blanchard,CG; Labreque,MS; Ruckdeschel,JC; Blanchard,EB (1988): Information and decision-making preferences of hospitalised adult cancer patients. *Soc.Sci.Med.* 27, 1139-1145.

Blanchard,CG; Labrecque,MS; Ruckdeschel,JC; Blanchard,EB (1990): Physician behaviours, patient perceptions, and patient characteristics as predictors of satisfaction of hospitalised adult cancer patients. *Cancer* 65, 186-192.

Bleiberg,H (1998): Continuing the fight against advanced colorectal cancer: new and future treatment options. *Anti-Cancer Drugs* 9 No.1, 18-28.

Bonnema,J; Wersch,MEA; Geel,AN; Pruyn,FA; Schmitz,PIM (1998): Medical and psychosocial effects of early discharge after surgery for breast cancer: randomised trial. *BMJ* 316, 1267-1271.

Boreham,P; Gibson,D (1978): The informative process in private medical consultations: a preliminary investigation. *Soc.Sci.Med.* 12, 409-416.

Botelho,RJ (1992): A negotiation model for the doctor-patient relationship. *Family Practice* 9 No2, 210-218.

Briefing Paper for the Executive Team, Avon Health Authority (1996): Briefing Paper.

- Britten,N (1995): Qualitative interviews in medical research. *BMJ* 311 22nd July, 251-253.
- Brock,DW; Wartman,SA (1990): When competent patients make irrational choices. *N.Eng.J.Med* 322 No22, 1595-1599.
- Brown,D et al (1994): Hard Choices: The gynecologic cancer patient's end-of-life preferences. *Gynecologic Oncology* 55, 355-362.
- Bruyn,ST (1984): The methodology of participant observation. In: *Qualitative Methodology: Firsthand Involvement with the Social World*. 1st ed. Vol. 1. (Ed: Filstead,WJ) Markham Publishing Company, Chicago, 305-325.
- Buchanan,J; Borland,R; Cosolo,W; Millership,R; Haines,I (1996): Patients' beliefs about cancer management. *Support Care Cancer* 4, 110-117.
- Buckman,R (1996): Talking to patients about cancer. *BMJ* 313, 699-700.
- Burgess,RG (1980): The Unstructured Interview as a Conversation. In: *Field Research: A Sourcebook and Field Manual*. (Ed: Burgess,RG) George Allen and Unwin, Boston, 107-110.
- Burish,TG; Redd,WH (1994): Symptom control in psychosocial oncology. *Cancer Supplement* 74 No4, 1438-1444.
- Burman,ME; Weinert,C (1997): Rural dwellers' cancer fears and perceptions of cancer treatment. *Public Health Nursing* 14 No.5, 272-279.
- Bury,M (1982): Chronic illness as biographical disruption. *Sociology of Health and Illness* 4 No2, 167-82.
- Bury,M (1997): Doctors, patients and interaction in health care. In: *Health and Illness in a Changing Society*. (Ed: Bury,M) Routledge, London, 77-109.
- Butow,PN; Maclean,M; Dunn,SM; Tattersall,MHN; Boyer,MJ (1997): The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann.Oncol.* 8 No.9, 857-863.
- Byers,T; Gorskiy,R (1992): Estimates of costs and effects of screening for colorectal cancer in the United States. *Cancer* 70 (supplement 5), 1288-1295.
- Byers,T; Levin,B; Rothenberger,D; Dodd,GD; Smith,RA (1997): American cancer society guidelines for screening and surveillance for early detection of colorectal polyps and cancer: update 1997: American Cancer Society Detection and Treatment Advisory Group on Colorectal Cancer. *ca* 47 No.3, 154-160.
- Cady,B; Jenkins,RL; Steele,GD; Lewis,WD; Stone,MD; McDermott,WV (1998): Surgical margin in hepatic resection for colorectal metastasis: a critical and improvable determinant of outcome. *Annals of Surgery* 227 No.4, 566-571.
- Calman,K; Hine,D (1995): A policy framework for commissioning cancer services. A report by the expert advisory group on cancer to the chief medical officers of England and Wales.
- Camaroff,J; Maguire,P (1981): Ambiguity and the search for meaning: childhood leukaemia in the modern clinical context. *Soc.Sci.Med.* 15B, 115-123.
- Cancer Research Campaign (1988): *Cancer Factsheets* 8.1, 9.1, 10.1. London.

Cannon,S (1989): Social research in stressful settings: difficulties for the sociologist studying the treatment of breast cancer. *Sociology* 11 No1, 62-77.

Capocaccia,R; De Angelis,R; Frova,L; Gatta,G; Sant,M; Micheli,A (1997): Estimation and projections of colorectal cancer trends in Italy. *International Journal of Epidemiology* 26 No.5, 924-932.

Carr-Hill,RA; Maynard,A; Slack,R (1990): Morbidity variation and RAWP. *Journal of Epidemiology and Community Health* 44, 271-273.

Casey,L; Zachariah,B; Balducci,L (1992): A profile of cancer patients aged 80 and older treated with radiation therapy: analysis of tolerance and effectiveness. *Journal of the American Geriatrics Society* 40 SA43, 23-34.

Casillas,S; Pelley,RJ; Milsom,JW (1997): Adjuvant therapy for colorectal cancer: present and future perspectives. *Dis.Colon.Rectum* 40 No.8, 977-992.

Cassileth,BR; Zupkis,RV; Sutton-Smith,K; March,V (1980): Information and participation preferences among cancer patients. *Annals of Internal Medicine* 92, 832-836.

Cassileth,BR; Lusk,EJ; Strouse,TB (1985): A psychological analysis of cancer patients and their next of kin. *Cancer* 55, 72-76.

Chadwick,D,J; Gillatt,D,A; Gingell,J,C (1991): Medical or surgical oophorectomy: the patients' choice. *BMJ* 302, 572.

Chapman,GB; Elstein,AS; Hughes,KK (1995): Effects of patient education on decisions about breast cancer treatments. *Medical Decision Making* 15, 231-239.

Charles,C; Gafni,A; Whelan,T (1997): Shared decision-making in the medical encounter: what does it mean? (Or it takes at least two to tango). *Soc.Sci.Med.* 44 No5, 681-692.

Charles,C; Redko,C; Whelan,T; Gafni,A; Reyno,L (1998): Doing nothing is no choice: lay constructions of treatment decision-making among women with early-stage breast cancer. *Sociology of Health and Illness* 20 No1, 71-95.

Coast,J; Richards,SH; Peters,TJ; Gunnell,DJ; Darlow,M (1998): Hospital at home or acute hospital care? a cost minimisation analysis. *BMJ* 316, 1802-1806.

Cooper,GS; Yuan,Z; Landefeld,CS; Rimm,AA (1996): Surgery for colorectal cancer - race related differences in rates and survival among medicare beneficiaries. *American Journal of Public Health* 86 No.4, 582-586.

Cooper,GS; Yuan,Z; Rimm,AA (1997): Racial disparity in the incidence and case-fatality of colorectal cancer: a analysis of 329 United States counties. *Cancer Epidemiology, Biomarkers and Prevention* 6 No.4, 283-285.

Corner,J (1991): In search of more complete answers to research questions. Quantitative versus qualitative research methods. is there a way forward? *Journal of Advanced Nursing* 16, 718-727.

Coulter,A (1991): Evaluating the outcomes of health care. In: *The Sociology of the Health Service*. 1st ed. (Eds: Gabe,J; Calnan,M; Bury,M) Routledge, London, 115-139.

Coulter,A (1997): Partnerships with patients: the pros and cons of shared clinical decision making. *J.Health.Serv.Res.Policy* 2 No2, 112-120.

Coulter,A; Mcpherson,K; Vessey,M (1988): Do British women undergo too many or too few hysterectomies? *Soc.Sci.Med.* 27 No.9, 987-994.

Coulter,A; Peto,V; Doll,H (1994): Patients' preferences and general practitioners' decisions in the treatment of menstrual disorders. *Family Practice* 11, 67-74.

Cox,SM; Mckellin,W (1999): 'There's this thing in our family': predictive testing and the construction of risk for Huntington's Disease. *Sociology of Health and Illness* 21 No5, 622-646.

Crump,BJ; Panton,R; Drummond,MF; Marchment,M; Hawkes,RA (1995): Transferring the cost of expensive treatments from secondary to primary care. *BMJ* 310, 509-512.

Davis,S; Wright,PW; Schulman,SF; Hill,LD; Pinkham,RD (1985): Participants in prospective, randomised clinical trials for resected non-small cell lung cancer have improved survival compared with nonparticipants in such trials. *Cancer* 56, 1710-1718.

Deber,R (1994): Physicians in health care management: 7.The patient-physician partnership:changing roles and the desire for information. *Can.Med.Assoc.J.* 151 No2, 171-176.

Deber,RB; Kraetschmer,N; Irvine,J (1996): What role do patients wish to play in treatment decision-making. *Archives of Internal Medicine* 156, 1414-1420.

Deber,R,B; Thompson,G (1990): Variations in breast cancer treatment decisions and their impact in mounting trials. *The Breast* 11 No5, 353-373.

Deber,R; Thompson,GG (1987): Who still prefers aggressive surgery for breast cancer?: implications for the clinical applications of clinical trials. *Annals of Internal Medicine* 107, 1543-1547.

Deber,RB (1994): Physicians in health care management: 8.The patient-physician partnership: decision making, problem solving and the desire to participate. *Can.Med.Assoc.J.* 151 No4, 423-427.

DeCossee,JJ; Cennerazzo,WJ (1997): Quality of life management of patients with colorectal cancer. *ca* 87 No.4, 198-206.

Degner,LF; Kristjanson,LJ; Bowman,D; Sloan,JA; Carriere,KC (1997): Information needs and decisional preferences in women with breast cancer. *Journal of the American Medical Association* 277, 1485-1492.

Degner,LF; Sloan,JA (1992): Decision making during serious illness: What role do patients really want to play? *Journal of clinical epidemiology* 45 No9, 941-950.

De Goede,E; Filez,L; Janssens,J; Van Cutsem,E (1998): Follow-up of colon cancer: detection of liver metastases: benefit and periodicity. *Acta Gastroenterologica Belgica* 61 No.1, 8-10.

Delbanco,TL (1992): Enriching the doctor-patient relationship by inviting the patient's perspective. *Annals of Internal Medicine* 116 No5, 414-417.

Del Vecchio Good,M; Munakata,T; Kobayashi,Y; Mattingly,C; Good,B (1994): Oncology and Narrative Time. *Soc.Sci.Med.* 38 No6, 855-862.

- Denzin,NK (1993): The handbook of qualitative research in education. *Contemporary Sociology – A Journal of Reviews* 22 No.2, 290-292.
- Dillner,L (1995): Britain's breast cancer services need overhaul. *BMJ* 311, 211-212.
- Dimatteo,MR; Friedman,HS; Taranta,A (1979): Sensitivity to bodily communication as a factor in practitioner-patient rapport. *J.Nonverbal.Behav.* 1, 18-26.
- Doherty,WJ; Baird,MA (Eds.) (1987): *Family-Centered Medical Care: A Clinical Casebook*. Guilford Press, New York. 234 pages.
- Dominitz,JA; Provenzale,D (1997): Patient preferences and quality of life associated with colorectal cancer screening. *The American Journal of Gastroenterology* 92 No.12, 2171-2178.
- Donovan,JM; Syngal,S (1998): Colorectal cancer in women: an underappreciated but preventable risk. *Journal of Women's Health* 7 No.1, 45-48.
- Dowie,J (1996): 'Evidence-based', 'cost effective' and 'preference-driven' medicine: decision analysis based medical decision making is the pre-requisite. *Journal of Health Services Research Policy* 1 No2, 104-113.
- Dowie,J (1998): The 'number needed to treat' and the 'adjusted NNT' in health care decision-making. *Journal of Health Services Research Policy* 3 No.1, 44-49.
- Downer,SM (1994): Pursuit and practice of complementary therapies by cancer patients receiving conventional treatment. *BMJ* 309, 86-89.
- Dunsmore,J; Quine,S (1995): Information, support and decision-making needs and preferences of adolescents with cancer: implications for health professionals. *Journal of Psychosocial Oncology* 13 No.4, 39-56.
- Dyer,C (1988): Inquiry found surgeon had high death rate for operation. *BMJ* 316, 1556.
- Eisenberg,JM (1979): Sociologic influences on decision making by clinicians. *Annals of Internal Medicine* 90, 957-964.
- Elit,LM et al (1996): Patients' preferences for therapy in advanced epithelial ovarian cancer: development, testing, and application of a bedside decision instrument. *Gynecologic Oncology* 62, 329-335.
- Elstein,AS (1976): Clinical judgement: psychological research and medical practice. *Science* 194, 696-700.
- Elwyn,TS; Feters,MD; Gorenflo,DW; Tsuda,T (1998): Cancer disclosure in Japan: historical comparisons, current practices. *Soc.Sci.Med.* 46 No.9, 1151-1163.
- England,SL; Evans,J (1992): Patients' choices and perceptions after an invitation to participate in treatment decisions. *Soc.Sci.Med.* 34 No11, 1217-1225.
- Epstein,RM; Campbell,TL; Cohen-Cole,SA; McWhinney,IR; Smilkstein,G (1993): Perspectives on patient-doctor communication. *J.Fam.Pract* 37, No4.
- Eraker,S; Kirscht,J; Becker,M (1984): Understanding and improving patient compliance. *Annals of Internal Medicine* 100, 258-268.

- Eraker,SA; Politser,P (1982): How decisions are reached: physician and patient. *Annals of Internal Medicine* 97, 262-268.
- Ershler,WB; Balducci,L (1994): Treatment considerations for older patients with cancer. *in.vivo.* 8, 737-744.
- Fahey,T; Griffiths,S; Peters,TJ (1995): Evidence based purchasing: understanding results of clinical trials and systematic reviews. *BMJ* 311, 1056-1059.
- Fallowfield,L (1993): Giving sad and bad news. *Lancet* 341, 476-478.
- Fallowfield,L (1995): Psychosocial interventions in cancer. *BMJ* 311, 1316-1317.
- Fallowfield,L (1997): Truth sometimes hurts but deceit hurts more. *Annals of the New York Academy of Sciences* 809, 525-538.
- Fallowfield,L; Baum,M; Maguire,GP (1986): Effects of breast conservation on psychological morbidity associated with diagnosis and treatment of early breast cancer. *British Medical Journal* 293, 1331-1334.
- Fallowfield,L; Ford,S; Lewis,S (1995): No news is not good news: information preferences of patients with cancer. *Psycho-Oncology* 4, 197-202.
- Fallowfield,L; Hall,A; Maguire,GP; Baum,M (1990): Psychological outcomes in women with early breast cancer. *BMJ* 301, 1394-1395.
- Fallowfield,LJ; Clark,AW (1994): Delivering bad news in gastroenterology. *The American Journal of Gastroenterology* 89 No4, 473-479.
- Fallowfield,LJ et al (1994): A question of choice: results of a prospective 3 year follow up study of women with breast cancer. *The Breast* 3, 202-208.
- Fallowfield,LJ; Hall,A; Maguire,GP; Baum,M (1990): Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *BMJ* 301 22nd September, 575-580.
- Ferrell,BR; Rivera,LM (1995): Ethical decision making in oncology. *Cancer.Practice.* 3 No2, 94-99.
- Field,D (1998): Special not different: general practitioners' accounts of their care of dying people. *Soc.Sci.Med* 46 No9, 1111-1120.
- Fischhoff,B (1975): Hindsight does not equal foresight: the effect of outcome knowledge on judgement under uncertainty. *J.Exp.Psychol.Hum.Percept* 41, 288-299.
- Fischhoff,B; Bostrom,A; Quadrel,MJ (1993): Risk perception and communication. *Annu.Rev.Publ.Health* 14, 183-203.
- Ford,S; Fallowfield,L; Lewis,S (1996): Doctor-patient interactions in oncology. *Soc.Sci.Med.* 42 No11, 1511-1519.
- Frankenberg,R (1980): Participant observers. In: *Field Research: A Sourcebook and Field Manual.* (Ed: Burgess,RG) George Allen and Unwin, Boston, 50-52.
- Freedman,B (1974): A moral theory of informed consent. *Hastings.Cent.Rep.* 5 No.32, 223-230.

Freidson,E (1970): Profession of Medicine: A Study of the Sociology of Applied Knowledge. 1st ed. University of Chicago Press, Chicago. 321 pages.

Friedman,MA; Trimble,EL; Abrams,JS (1994): Tamoxifen: trials, tribulations and trade offs. J.Natl.Cancer.Inst 86 No7, 478-479.

Gafni,A (1990): Competent patients and irrational choices. N.Eng.J.Med 323 No.19, 1354.

Galloway,SC; Graydon,JE (1996): Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. Cancer.Nurs. 19 No.2, 112-117.

Gans,HJ (1980): The participant observer as human being: observations on the personal aspects of fieldwork. In: Field Research: A Sourcebook and Field Manual. (Ed: Burgess,RG) George Allen and Unwin, Boston, 53-61.

Ganz,PA; Schag,AC; Lee,J; Polinski,ML; Tan,SJ (1992): Is there a difference in psychological adjustment or quality of life in the year after surgery? Cancer 69 No.7, 1729-1738.

Ganz,PA; Schag,CC; Heinrich,RL (1985): The psychosocial impact of cancer on the elderly: a comparison with younger patients. J.Am.Geriatr.Soc. 33 No6, 429-435.

Garro,LY (1982): The Ethnography of Health Care Decisions. Soc.Sci.Med. 16, 1451-1452.

Gatta,G; Sant,M; Coebergh,JW; Hakulinen,T (1996): Substantial variation in therapy for colorectal cancer across Europe: Eurocare analysis of cancer registry data for 1987. European Journal of Cancer Care 32A No.5, 831-835.

Glaser,BG; Strauss,AL (Eds.) (1967): The Discovery of Grounded Theory. Aldine Publishing Company, Chicago. 183 pages.

Goffman,E (1971): The Presentation of Self in Everyday Life. 1st ed. Penguin Books, Harmondsworth. 267 pages.

Gold,R (1958): Roles in sociological field investigation. Social Forces 36, 217-223.

Goldberg,D (1986): Use of the general health questionnaire in clinical work. BMJ 293, 1188-1189.

Goldberg,D; Williams,P (Eds.) (1988): A Users Guide to the General Health Questionnaire. The Nfer-Nelson Publishing Company, Oxford. 97 pages.

Goldberg,RJ; Cullen,LO (1985): Factors important to psychosocial adjustment to cancer: a review of the evidence. Soc.Sci.Med. 20 No8, 803-807.

Golin,CE; Dimatteo,MR; Gelberg,L (1996): The role of patient participation in the doctor visit. Diabetes Care 19 No10, 1153-1165.

Goodwin,JS; Hunt,WC; Samet,JM (1993): Determinants of cancer therapy in elderly patients. Cancer 72 No.2, 594-601.

Goodwin,JS; Nattinger,AB (1995): Effect of season and climate on choice of therapy for breast cancer in older women. Journal of the American Geriatrics Society 43, 962-966.

Graupe,F; Schwenk,W; Bracht,B; Kronerherwig,B; Stock,W (1996): Psychological strain of patients in a follow-up program after curative resection for colorectal carcinoma. *Chirurg* 67 No.6, 604-609.

Gray,RE; Doan,BD (1990): Empowerment and persons with cancer: Politics in cancer medicine. *J.Palliat.Care.* 6 No2, 33-45.

Graydon,J; Galloway,S; Palmer,WS; Harrison,D; Richvanderbij,L (1997): Information needs of women during early treatment for breast cancer. *Journal of Advanced Nursing* 26 No.1, 59-64.

Gregory,DR; Cotler,MP (1994): The problem of futility:III. The importance of physician-patient communication and a suggested guide through the minefield. *Cambridge Quarterly of Healthcare Ethics* 3, 257-269.

Grunfeld,E; Mant,D; Vessey,MP; Fitzpatrick,R (1995): Specialist and general practice views on routine follow-up of breast cancer patients in general practice. *Family Practice* 12 No.1, 60-65.

Hack,TF(1994): Relationship between preferences for decisional control and illness information among women with breast cancer:A quantitative and qualitative analysis. *Soc.Sci.Med.* 39, 279-289.

Haigh,C (1993): Sick role and the cancer patient. *European Journal of Cancer Care* 2, 21-23.

Hammersley,M (1992) *What's Wrong with Ethnography?* London: Routledge.

Harding,MJ; Paul,J; Gillis,CR; Kaye,SB (1993): Management of malignant teratoma: does referral to a specialist unit matter? *Lancet* 341, 999-1002.

Hart,AR; Barone,TL; Mayberry,JF (1997): Increasing compliance with colorectal cancer screening: the development of effective health education. *Health Education Research* 12 No.2, 171-180.

Hayman,JA; Fairclough,DL; Harris,JR; Weeks,JC (1997): Patient preferences concerning the trade-off between the risks and benefits of routine radiation therapy after conservative surgery for early stage breast cancer. *J.Clin.Oncol* 15 No.3, 1252-1260.

Hazen,GB; Hopp,WJ; Pellissier,JM (1991): Continuous risk utility assessment in medical decision-making. *Medical Decision Making* 11, 294-304.

Hebert,P; Hoffmaster,B; Glass,KC; Singer,PA (1997): Bioethics for clinicians:7.Truth telling. *Canadian Medical Association Journal* 156 No2, 225-228.

Henbest,RJ; Stewart,M (1990): Patient-centeredness in the consultation. 2: Does it really make a difference? *Family Practice* 7 No1, 28-33.

Henschke,U; Flehinger,B (1967): Decision theory in cancer therapy. *Cancer* 20, 1819-1826.

Herbert,C; Launoy,G; Thezee,Y; Maurel,J; Richir,B; Reaud,JM (1995): Participants' characteristics in a French colorectal cancer mass screening campaign. *Preventive Medicine* 24 No.5, 498-502.

Hinds,C; Streater,A; Mood,D (1995): Functions and preferred methods of receiving information related to radiotherapy. *Cancer.Nurs.* 18 No.5, 374-384.

- Hughes,KK (1993): Psychosocial and functional status of breast cancer patients. *Cancer.Nurs.* 16 No3, 222-229.
- Irvine,D; Brown,B; Crooks,D; Roberts,J; Browne,G (1991): Psychosocial adjustment in women with breast cancer. *Cancer* 67 No4 February 15, 1097-1117.
- James,V and Gabe,J (1996): *Connecting Emotions and Health*. In: *Health and the Sociology of Emotions*. (Ed: James,V and Gabe,J) Blackwell, Oxford, 1-23.
- Jenkins,R (1992): *Pierre Bourdieu*. 1st ed. Vol. 1. The Open University, Milton Keynes. 190 pages.
- Jensen,PS (1981): The doctor-patient relationship: headed for impasse or improvement? *Annals of Internal Medicine* 95, 769-771.
- Johnson,JD; Roberts,CS; Cox,CE; Reintgen,DS; Levine,JS; Parsons,M (1996): Breast cancer patients' personality style, age, and treatment decision making. *J.Surg.Oncol.* 63, 183-186.
- Jolley,MG (1988): Ethics of cancer management from the patient's perspective. *Journal of Medical Ethics* 14, 188-190.
- Jones,J; Hunter,D (1995): Consensus methods for medical and health services research. *BMJ* 311, 376-380.
- Junor,EJ; Hole,DJ; Gillis,CR (1994): Management of ovarian cancer: referral to a multidisciplinary team matters. *British Journal of Cancer* 70, 363-370.
- Karjalainen,S; Palva,I (1989): Do treatment protocols improve end results? A study of survival of patients with multiple myeloma in Finland. *BMJ* 299, 1069-1072.
- Kehoe,S; Powell,J; Wilson,S; Woodman,C (1994): The influence of the operating surgeon's specialisation on patient survival in ovarian carcinoma. *British Journal of Cancer* 70, 1014-1017.
- Kelly,MP; Field,D (1996): Medical sociology, chronic illness and the body. *Sociology of Health and Illness* 18 No2, 241-257.
- Kelly-Powell,ML (1997): Personalizing choices: patients' experiences with making treatment decisions. *Research in Nursing and Health* 20, 219-227.
- Kerr,DJ; Griffiths,R; Edwards,B (1996): Delivering cancer care: a model from the West Midlands. *British Journal of Cancer* 74, 667-669.
- Kessel,AS (1994): On failing to understand informed consent. *British Journal of Hospital Medicine* 52 No5, 235-238.
- King,MC; Rowell,S; Love,SM (1993): Inherited breast and ovarian cancer: what are the risks? what are the choices? *Journal of the American Medical Association* 269 No.15, 23-45.
- Kingston,RD; Walsh,S; Jeacock,J (1992): Colorectal surgeons in district general hospitals produce similar survival outcomes to their teaching hospital colleagues: review of 5-year survivals in Manchester. *J.R.Coll.Surg.Edinb.* 37, 235-237.
- Klein,R (1995): Priorities and rationing: pragmatism or principles? *BMJ* 311, 761-762.

Klein,R; Day,P; Redmayne,S (1996): Managing Scarcity: Priority Setting and Rationing in the National Health Service. Open University Press, Buckingham. 161 pages.

Koperna,T; Kisser,M; Schulz,F (1998): Hepatic resection in the elderly. World Journal of Surgery 22 No.4, 406-412.

Korsch,BM; Gozzi,EK; Francis,V (1968): Gaps in doctor-patient communication. Pediatrics 42, 855-871.

Labianca,R; Pessi,MA; Zamparelli,G (1997): Treatment of colorectal cancer. Current guidelines and future prospects for drug therapy. Drugs 54 No.1, 160.

Labrecque,MS; Blanchard,CG; Ruckdeschel,John,C; Blanchard,Edward,B (1991): The impact of family presence on the physician-cancer patient interaction. Soc.Sci.Med. 33 No11, 1253-1261.

Laine,C; Davidoff,F (1996): Patient centered medicine: a professionsl evolution. Journal of the American Medical Association 275 No2, 152-156.

Laslett,B; Rapoport,R (1975): Collaborative interviewing and interactive research. Journal of Marriage and the Family 37, 968-977.

Leard,LE; Savides,TJ; Ganiats,TG (1997): Patient preferences for colorectal cancer screening. J.Fam.Pract 45 No.3, 211-218.

Lee,R (Ed.) (1993): Doing Research on Sensitive Topics. Sage, London. 248 pages.

Levine,MN; Gafni,A; Markham,B; McFarlane,D (1992): A bedside decision instrument to elicit a patient's preference concerning adjuvant chemotherapy for breast cancer. Annals of Internal Medicine 117 No1, 53-58.

Lewis,M; Pearson,V; Corcoran-Perry,S; Narayan,S (1997): Decision-making by elderly patients with cancer and their caregivers. Cancer.Nurs. 20 No.6, 389-397.

Liberati,A; Apolone,G; Nicolucci,A; Confalonien,C; Fossati,R; Grilli,R; Torri,V (1990): The role of attitudes, beliefs, and personal characteristics of Italian physicians in the surgical treatment of early breast cancer. American Journal of Public Health 81 No1, 38-42.

Llewellyn Thomas,H; Cohen,MM; Basinski,ASH; Ferris,LE; Williams,JI (1992): Studying patients' preferences in health care decision making. Canadian Medical Association Jornal 147 No6, 859-864.

Llewellyn-Thomas,H,A; McGreal,M,J; Thiel,E,C; Fine,S (1991): Patients' willingness to enter clinical trials: measuring the association with perceived benefit and preference for decision participation. Soc.Sci.Med. 32 No1, 35-42.

Long,DS (1993): How breast cancer patients choose a treatment method. Radiologic Technology 65 No1, 30-33.

Luhmann,N (1979): Trust and Power. John Wiley and Sons, Great Britain. 208 pages.

Luker,KA; Beaver,K; Leinster,SJ; Owens,RG (1996): Information needs and sources of information for women with breast cancer: a follow-up study. Journal of Advanced Nursing 23 No.3, 487-495.

- Lupton,D; Donaldson,C; Lloyd,P (1991): Caveat emptor or blissful ignorance? Patients and the consumerist ethos. *Soc.Sci.Med.* 33 No5, 559-568.
- Lupton,D (1996): Your life in their hands: trust in the medical encounter. In: *Health and the Sociology of Emotions.* (Ed: James,V and Gabe,J) Blackwell, Oxford, 157-173.
- Mackillop,WJ; Stewart,WE; Ginsburg,AD; Stewart,SS (1988): Cancer patients' perceptions of their disease and treatment. *British Journal of Cancer* 58, 355-358.
- Mandelblatt,J; Andrews,H; Kao,R; Wallace,R; Kerner,J (1996): The late-stage diagnosis of colorectal cancer: demographic and socioeconomic factors. *American Journal of Public Health* 86 No.12, 1794-1797.
- Manfredi,C; Czaja,R; Buis,M; Derk,D (1993): Patient use of treatment-related information received from the cancer information service. *Cancer* 71 No4, 1326-1337.
- Margalith,I; Shapiro,A (1997): Anxiety and patient participation in clinical decision-making: the case of patients with ureteral calculi. *Soc.Sci.Med.* 45 No.3, 419-427.
- Marmot,M (1996): From alcohol and breast cancer to beef and BSE-improving our communication of risk. *American Journal of Public Health* 86 No7, 921-923.
- Marteau,TM (1995): Towards informed decisions about prenatal testing: areview. *Prenat.Diagn.* 15, 1215-1226.
- Marvel,KM; Schilling,R; Doherty,WJ (1994): Levels of physician involvement with patients and their families. *J.Fam.Pract* 39 No6(Dec), 535-541.
- Mathews,JJ (1983): The communication process in clinical settings. *Soc.Sci.Med.* 17 No18, 1371-1378.
- Matthews,HR; Powell,DJ; McConkey,CC (1986): Effect of surgical experience on the results of resection for oesophageal carcinoma. *Br.J.Surg* 73, 621-623.
- May,T (1993): The method of participant observation. In: *Social Research: Issues Methods and Process.* 1st ed. Vol. 1. (Ed: May,T) Open University Press, Buckingham, 111-132.
- Maynard,A (1997): Evidence-based medicine: an incomplete method for informing treatment choices. *Lancet* 349, 126-128.
- Mays,N; Pope,C (1995): Observational methods in health care settings. *British Medical Journal* 311, 182-184.
- Mazur,DJ; Hickam,DH (1996): Patient preferences for management of localized prostate cancer. *West.J.Med.* 165, 26-30.
- Mazur,DJ; Hickman,DH (1997): The influence of physician explanations on patient preferences about future health-care states. *Medical Decision Making* 17 No.1, 56-60.
- Mazur,DJ; Merz,JF (1993): How the manner of presentation of data influences older patients in determining their treatment preferences. *Journal of the American Geriatrics Society* 41 No.3, 223-228.
- McArdle,CS; Hole,D (1991): Impact of variability among surgeons on postoperative morbidity and mortality and ultimate survival. *British Medical Journal* 302 No6791, 1501-1505.

Mcdowell,I; Newell,C (eds) (1996): *Measuring Health. A Guide to Rating Scales and Questionnaires*. Open University Press, Oxford. 134 pages.

McGinnis,LS (1994): Surgical treatment options for colorectal cancer. *Cancer* 74, 2147-2150.

McGrath,P (1995): It's ok to say no! A discussion of ethical issues arising from informed consent to chemotherapy. *Cancer.Nurs.* 18 No2, 97-103.

McIntosh,J (1976): Patients' awareness and desire for information about diagnosed but undisclosed malignant disease. *Lancet* 7, 300-303.

Mcquellon,R; Muss,HB; Hoffman,SL; Russell,G; Craven,B; Yellen,SB (1995): Patient preferences for treatment of metastatic breast cancer: a study of women with early-stage breast cancer. *J.Clin.Oncol* 13 No4, 858-868.

Meredith,C; Symonds,P; Webster,L; Lamont,D; Pyper,E; Gillis,CR; Fallowfield,L (1996): Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. *BMJ* 313, 724-726.

Meredith,P (1993a): Patient participation in decision making and consent to treatment: the case of general surgery. *Sociology* 15 No3, 35-57.

Meyer,BJF; Russo,C; Talbot,A (1995): Discourse comprehension and problem solving:decisions about the treatment of breast cancer by women across the life span. *Psychol.Aging.* 10 No1, 84-103.

Miles,MB; Huberman,AM (Eds.) (1994): *Qualitative Data Analysis*. 2nd ed. Sage, London. 338 pages.

Mitsuya,H (1997): Telling the truth to cancer patients and patients with HIV-1 infection in Japan. *Annals of the New York Academy of Sciences* 809, 279-289.

Miyaji,N (1993): The power of compassion: truth telling among American doctors in the care of dying patients. *Soc.Sci.Med.* 36 No3, 249-264.

Morgan,M; Beech,R (1990): Variations in lengths of stay and rates of day case surgery: implications for the efficiency of surgical management. *Journal of Epidemiology and Community Health* 44, 90-105.

Morris,J; Ingham,R (1988): Choice of surgery for early breast cancer: psychosocial considerations. *Soc.Sci.Med.* 27 No11, 1257-1262.

Morris,J; Royle,GT (1988): Offering patients a choice of surgery for early breast cancer: a reduction in anxiety and depression in patients and their husbands. *Soc.Sci.Med.* 26 No6, 583-585.

Moss,ED; Cronau,JR (1995): Ethical issues in surgical oncology patients. *The Cancer Bulletin* 47 No.1, 74-77.

Mushinski,M (1998): Variation in in-hospital charges for colorectal cancer treatment. *Statis.Bull.* 79 No1, 19-27.

- Nayfield,SG; Bongiovanni,GC; Alciati,MH; Fischer,RA; Bergner,L (1994): Statutory requirements for disclosure of breast cancer treatment alternatives. *J.Natl.Cancer.Inst* 86 No16, 1202-1208.
- Nelson,RL (1993): The decision to treat patients with recurrent colorectal cancer. *Cancer Supplement* 71 No12, 4298-4301.
- Norum,J (1997): Adjuvant chemotherapy in Duke's B and C colorectal cancer has only a minor influence on psychological distress. *Supportive Care in Cancer* 5 No.4, 318-321.
- Novack,D; Plumer,R; Smith,R; Ochtil,H; Morrow,G; Bennett,J (1979): Changes in physicians' attitudes toward telling the cancer patient. *Journal of the American Medical Association* 241, 897-900.
- Oakley,A (Ed.) (1980): *Women Confined: Towards a Sociology of Childbirth*. Martin Robertson, Oxford. 252 pages.
- Oakley,A (1981): Interviewing women: a contradiction in terms. In: *Doing Feminist Research*. 1st ed. Vol. 1. (Ed: Roberts,H) Routledge, London, 30-59.
- Onel,E; Hamond,C; Wasson,JH; Berlin,BB; Ely,MG; Laudone,VP (1998): Assessment of the feasibility and impact of shared decision-making in prostate cancer. *Urology* 51 No.1, 63-66.
- Ong,LML; De Haes,JCJM; Hoos,AM; Lammes,FB (1995): Doctor-patient communication: a review of the literature. *Soc.Sci.Med.* 40 No7, 903-918.
- Orsi,AJ; McCorkle,R; Tax,AW; Barsevick,A (1996): The relationship between depressive symptoms and immune status phenotypes in patients undergoing surgery for colorectal cancer. *Psycho-Oncology* 5 No.4, 311-319.
- Parshad,R (1997): Adjuvant therapy in colorectal cancer. *Tropical Gastroenterology* 18 No.4, 139-144.
- Parsons,E; Atkinson,P (1992): Lay constructions of genetic risk. *Sociology of Health and Illness* 14 No4, 437-455.
- Parsons,T (1951): *The Social System*. 1st ed. Free Press, New York. 237 pages.
- Pauker,SG; Kassirer,J,P (1987): Decision Analysis. *N.Eng.J.Med* Vol 316 No 5, 250-258.
- Pauker,SG; Kassirer,JP (1980): The threshold approach to clinical decision making. *N.Eng.J.Med* 302 No20, 1109-1117.
- Petrisek,AC; Laliberte,LL; Allen,SM; Mor,V (1997): The treatment decision-making process: age differences in a sample of women recently diagnosed with nonrecurrent, early stage breast cancer. *The Gerontologist* 37 No.5, 598-608.
- Petrisek,AC; Laliberte,LL; Allen,SM; Mor,V (1998): The treatment decision-making process: age differences in a sample of women recently diagnosed with nonrecurrent, early stage breast cancer. *The Gerontologist* 37 No.5, 598-608.
- Pierce,P (1993): Deciding on breast cancer treatment: a description of decision behaviour. *N.R.* 42 No1, 22-28.

- Pietroni,P; Chase,DH (1993): Partners or partisans? patient participation at Marylebone health centre. *British Journal of General Practice* 43, 341-344.
- Pollock,AM; Vickers,N (1997): Management of colorectal cancer in three South Thames District Health Authorities. *Public Health* 111 No.3, 165-170.
- Pope,C; Mays,N (1995): Researching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 311, 42-45.
- Quill,Timothy,E (1983): Partnerships in patient care: A contractual approach. *Annals of Internal Medicine* 98, 228-234.
- Quine,L; Rutter,DR (1994): First diagnosis of severe mental and physical disability: a study of doctor-patient communication. *J.Child.Psychol.Psychiat.* 35 No7, 1273-1287.
- Rasinski,D; Cotler,G; Cotler,M (1994): The problem of futility: III. The importance of physician-patient communication and a suggested guide through the minefield. *Cambridge Quarterly of Healthcare Ethics* 3, 257-269.
- Raudonis,BM (1992): Ethical considerations in qualitative research with hospice patients. *Qualitative Health Research* 2 No2, 238-249.
- Razavi,D; Delvaux,N; Hopwood,P (1997): Improving communication with cancer patients. *Annals of the New York Academy of Sciences* 809, 350-360.
- Reaby,LL (1998): The quality and coping patterns of women's decision-making regarding breast cancer surgery. *Psycho-Oncology* 7 No.3, 252-262.
- Redelmeier,DA; Rozin,P; Kahneman,D (1993): Understanding patients' decisions. *Journal of the American Medical Association* 270 No1, 72-76.
- Redmayne,S (1995): Reshaping the NHS: strategies, priorities and resource allocation. *National Association of Health Authorities and Trusts*.
- Redmayne,S (1996): Small steps big goals: purchasing policies in the NHS. *National Association of Health Authorities and Trusts*.
- Redmond,K (1998): Assessing patients needs and preferences in the management of advanced colorectal cancer. *British Journal of Cancer* 77, 5-7.
- Reynolds,PM; Sanson-Fisher,RW; Poole,DA; Harker,J; Byrne,MJ (1981): Cancer and communication: information giving in an oncology clinic. *British Medical Journal* 282, 1449-1451.
- Rhodes,T; Cusick,L (2000): Love and intimacy in relationship risk management: HIV positive people and their sexual partners. *Sociology of Health and Illness* 22 No1, 1-26.
- Richards,M (1996): Families, kinship and genetics. In: *The Troubled Helix: Social and Psychological Implications of the New Genetics*. 1st ed. Vol. 1. (Eds: Marteau,T; Richards,MPM) Cambridge University Press, Cambridge, 359.
- Richards,MPM; Hallowell,N; Green,JM; Murton,F; Statham,H (1995): Counselling families with hereditary breast and ovarian cancer: a psycho-social perspective. *Journal of Genetic Counselling* 4, 219-233.

Risko,A; Fleischmann,T; Molnar,Z; Schneider,T; Varady,E (1996): Influence of the pathological psychological state of cancer patients on their decisions. *Support Care Cancer* 4, 51-55.

Ritchie,J; Spencer,L (1994): Qualitative data analysis for applied policy research. In: *Analysing Qualitative Data*. (Eds: Bryman,A; Burgess,RG) Allen and Unwin, London, 237.

Roberts,CS; Cox,CE; Reintgen,DS; Baile,WF; Gibertini,M (1994): Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making. *Cancer Supplement* 74 No1, 336-341.

Robinson,B; Balducci,L (1995): Breast lump in an 85 year old woman with dementia: a decision analysis. *J.Am.Geriatr.Soc.* 43 No3, 282-285.

Rodriguez-Marin,J; Lopez-Roig,S; Pastor,MA (1996): Doctors' decision-making on giving information to cancer patients. *Psychology and Health* 11, 839-844.

Rothenbacher,D; Lutz,MP; Porzsolt,F (1997): Treatment decisions in palliative cancer care: patients' preferences for involvement and doctors' knowledge about it. *European Journal of Cancer Care* 33 No.8, 1184-1189.

Rougier,P; Neoptolemos,JP (1997): The need for a multidisciplinary approach in the treatment of advanced colorectal cancer: a critical review from a medical oncologist and surgeon. *European Journal of Surgical Oncology* 23 No.5, 385-396.

Sandison,AJP; Gold,DM; Wright,P; Jones,PA (1996): Breast conservation or mastectomy:treatment choice of women aged 70 years and older. *Br.J.Surg* 83, 994-996.

Sardell,AN; Trierweiler,SJ (1993): Disclosing the cancer diagnosis. *Cancer* 72 No11 December 1, 3355-3365.

Sargeant,K (1995): Patient participation in decisionmaking. *Can.Med.Assoc.J.* 152 No1, 13-14.

Schapira,MM; Meade,C; Nattinger,AB (1997): Enhanced decision-making: the use of a videotape decision-aid for patients with prostate cancer. *Patient Education and Counseling* 30, 119-127.

Schover,LR (1995): Partial mastectomy and breast reconstruction: a comparison of their effects on psychosocial adjustment, body image and sexuality. *Cancer* 75 No1, 54-64.

Schraub,S; Arveux,P; Mercier,M (1995): Cancer screening psychosocial consideration. *Bulletin Du Cancer* 82 No.8, 607-610.

Sensky,T; Catalan,J (1992): Asking patients about their treatment. *BMJ* 305 November 7, 1109-1110.

Shepperd,S; Harwood,D; Gray,A; Vessey,M; Morgan,P (1998b): Randomised controlled trial comparing hospital at home care with inpatient hospital care.II: cost minimisation analysis. *BMJ* 316, 1791-1796.

Shepperd,S; Harwood,D; Jenkinson,C; Gray,A; Vessey,M; Morgan,P (1998a): Randomised controlled trial comparing hospital at home care with inpatient hospital care.I: three month follow up of health outcomes. *BMJ* 316, 1786-1790.

Silliman,RA; Dukes,KA; Sullivan,LM; Kaplan,SH (1998): Breast cancer care in older women - sources of information, social support, and emotional health outcomes. *Cancer* 83 No.4, 706-711.

Silverman,D (1993): Theory and method in qualitative research. In: *Interpreting Qualitative Data*. first ed. Vol. 1. (Ed: Silverman,D) Sage, London, 1-19.

Silverman,D (1993): Observation. In: *Interpreting Qualitative Data*. first ed. Vol. 1. (Ed: Silverman,D) Sage, London, 30-58.

Silverman,W (1995): Effectiveness, efficiency and subjective choice. *Pers.Biolog.Medic.* 38 No3, 480-495.

Siminoff,LA; Fetting,JH (1991): Factors affecting treatment decisions for life threatening illness: the case of medical treatment for breast cancer. *Soc.Sci.Med.* 32, 813-818.

Siminoff,LA; Fetting,JH; Abeloff,MD (1989): Doctor-patient communication about breast cancer adjuvant therapy. *J.Clin.Oncol* 7, 1192-1200.

Simpson,M; Buckman,R; Stewart,M; Maguire,P; Lipkin,M; Novack,D; Till,J (1991): Doctor-patient communication: the Toronto consensus statement. *BMJ* 303, 30th Nov, 1385-1387.

Slevin,ML; Stubbs,L; Plant,HJ; Wilson,P; Gregory,WM; Armes,PJ; Downer,SM (1990): Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors, nurses, and general public. *BMJ* 300, 1458-1460.

Smith,SJ; Muir,KR; Wolstenholme,JL; Thornhill,KG; Zamorski,A (1997): Continued inadequacies in data sources for the evaluation of cancer services. *British Journal of Cancer* 75 No.1, 131-133.

Smith,TJ; Bodurtha,JN (1995): Ethical considerations in oncology:balancing the interests of patients, oncologists, and society. *J.Clin.Oncol* 13 No9, 2464-2470.

Soderlund,N; Csaba,I; Gray,A; Milne,R; Raftery,J (1997): Impact of the NHS reforms on English hospital productivity: an analysis of the first three years. *BMJ* 315, 1126-1129.

Speedling,EJ; Rose,DN (1985): Building an effective doctor-patient relationship:from patient satisfaction to patient participation. *Soc.Sci.Med.* 21 No.2, 115-120.

Stewart,MA (1984): What is a successful doctor-patient interview? A study of interactions and outcomes. *Soc.Sci.Med.* 19 No2, 167-175.

Strauss,AL (Ed.) (1987): *Qualitative Analysis for Social Scientists*. Cambridge University Press, Cambridge. 319 pages.

Strauss,AL and Corbin,J (1997): *Grounded Theory in Practice*. Chicago.

Street,RL; Voigt,B; Geyer,C; Manning,T; Swanson,GP (1995): Increasing patient involvement in choosing treatment for early breast cancer. *Cancer* 76 No.11, 2275-2285.

Strull,WM; Lo,B; Charles,G (1984): Do patients want to participate in medical decision making? *Journal of the American Medical Association* 252 No21, 2990-2994.

Sutherland,HJ; Lockwood,GA; Tritchler,DL; Brooks,L; Till,JE (1991): Communicating probabilistic information to cancer patients: is there noise on the line? *Soc.Sci.Med.* 32 No6, 725-731.

Sutherland,H,J; Llewellyn-Thomas,H,A; Lockwood,G,A; Tritchler,D,L; Till,J,E (1989): Cancer patients:their desire for information and participation in treatment decisions. *Journal of the Royal Society of Medicine* 82, 260-263.

Szasz,TS; Hollender,MH (1956): A contribution to the philosophy of medicine: the basic models of the doctor-patient relationship. *Archives of Internal Medicine* 97, 585-592.

Tabak,N (1995): Decision making in consenting to experimental cancer therapy. *Cancer.Nurs.* 18 No2, 89-96.

Tarbox,B; Rockwood,J; Abernathy,C (1992): Are modified radical mastectomies done for T1 bresat cancers because of surgeon's advice or patient's choice? *Am.J.Surg.* 164, 417-422.

Taylor,SE; Lichtman,RR; Wood,JV (1985): Illness-related and treatment-related factors in psychological adjustment to breast cancer. *Cancer* 55, 2506-2513.

Thomas,RJ; Clarke,VA (1998): Community (mis)understanding of colorectal cancer treatment. *Aust.N.Z.J.Surg.* 68 No.5, 328-330.

Thompson,SC; Pitts,JS; Schwankowski,L (1993): Preferences for involvement in medical decision-making: situational and demographic influences. *Patient Education and Counselling* 22, 133-140.

Thomsen,OO; Wulff,HR; Martin,A; Singer,PA (1993): What do gastroenterologists in Europe tell cancer patients? *Lancet* 341, 473-478.

Torfs,K; Pocceschi,S (1996): A retrospective study of resource utilisation in the treatment of advanced colorectal cancer in Europe. *European Journal of Cancer Care* 32A No.S5, 28-31.

Tucket,D; Boulton,M; Olson,C; Williams,A (1985): *Meetings Between Experts*. 1st ed. Tavistock, London. 345 pages.

Turkcharles,S; Meyerowitz,BE; Gatz,M (1997): Age differences in information-seeking among cancer patients. *International Journal of Aging and Human Development* 45 No.2, 85-98.

Tversky,A; Kahneman,D (1974): Judgment under uncertainty: heuristics and biases. *Science* 185, 1124-1131.

Ulander,K; Jeppsson,B; Grahn,G (1997): Quality of life and independence in activities of daily living preoperatively and at follow-up in patients with colorectal cancer. *Supportive Care in Cancer* 5 No.5, 402-409.

Van der Donk,J; Levendag,PC; Kuijpers,AJ; Roest,FHJ; Habbema,JDF (1995): Patient participation in clinical decision-making for treatment of T3 laryngeal cancer: a comparison of state and process utilities. *J.Clin.Oncol* 13 No.9, 2369-2378.

Vanwersch,A; Bonnema,J; Prinsen,B; Pruyn,J; Wiggers,T; Vangeel,AN (1997): Continuity of information for breast cancer patients: the development, use and evaluation of a multidisciplinary care protocol. *Patient Education and Counseling* 30 No.2, 175-186.

Vanwersch,A; deBoer,MF; VanderDoes,E; deJong,P; Knegt,P (1997): Continuity of information in cancer care: evaluation of a logbook. *Patient Education and Counseling* 31 No.3, 223-236.

Vaughn,DJ; Haller,DG (1997): The role of adjuvant chemotherapy in the treatment of colorectal cancer. *Hematology* 11 No.4, 699-719.

Veatch,RM; Stempsey,WE (1995): Incommensurability: its implications for the patient/physician relation. *Journal of Medicine and Philosophy* 20, 253-269.

Verhoef,L; Stalpers,LJA; Verbeek,ALM; Wobbes,T; Daal,WAJ (1991): Breast conserving treatment or mastectomy in early breast cancer: a clinical decision analysis with special reference to the risk of local recurrence. *European Journal of Cancer Care* 27 No9, 1132-1137.

Vernon,SW; Hughes,JI; Heckel,VM; Jackson,GL (1992): Quality of care for colorectal cancer in a fee-for-service and Health Maintenance Organisation practice. *Cancer* 69 No.10, 2418-2425.

Vidich (1961): Participant observation and the collection and interpretation of data. In: *Qualitative Methodology*. (Ed: Filstead,WJ) Markham Publishing Company, Chicago, 164-185.

Violi,V; Pietra,N; Grattarola,M; Sarli,L; Choua,O; Roncoroni,L (1998): Curative surgery for colorectal cancer: long-term results and life expectancy in the elderly. *Dis.Colon.Rectum* 41 No.3, 291-298.

Wagner,RF; Torres,A; Proper,S (1995): Informed consent and informed refusal. *Dermatol.Surg.* 21, 555-559.

Waitzkin,Howard (1979): Medicine superstructure and micropolitics. *Soc.Sci.Med.* 13A, 601-609.

Ward,S; Heidrich,S; Wolberg,W (1989): Factors women take into account when deciding upon type of surgery for breast cancer. *Cancer.Nurs.* 12, No.6, 344-351.

Weale,A (1998): Rationing health care: a logical solution to an inconsistent triad. *BMJ* 316, 410.

Weeks,JC; Cook,EF; O'Day,SJ; Peterson,LM; Wenger,N; Reding,D (1998): Relationship between cancer patients' predictions of prognosis and their treatment preferences. *Journal of the American Medical Association* 279 No.21, 1709-1714.

Weil,M; Khayat,D (1994): Truth telling to cancer patients in the western european context. *Psycho-Oncology* 3, 21-26.

Weller,DP; Owen,N; Hiller,JE; Willson,K; Wilson,D (1995): Colorectal cancer and its prevention - prevalence of beliefs, attitudes, intentions and behaviour. *Australian Journal of Public Health* 19 No.1, 19-23.

Whitehouse,M (1995): A policy framework for commissioning cancer services. *BMJ* 310, 1425-1426.

Whynes,DK; Neilson,AR (1997): Symptoms before and after surgery for colorectal cancer. *Quality of Life Research* 6 No.1, 61-66.

Whyte,WF (1980): Interviewing in field research. In: *Field Research: A Sourcebook and Field Manual*. (Ed: Burgess,RG) George Allen and Unwin, Boston, 111-121.

Williams,CJ (1995): Knowing just how effective is treatment: implications for care of cancer patients. *Clin.Oncol.* 7, 42-45.

Williams,G; Popay,J (1994): Lay knowledge and the privilege of experience. In: *Challenging Medicine*. 1st ed. Vol. 1. (Eds: Gabe,J; Kelleher,D; Williams,G) Routledge, London, 118-139.

Williams,SJ (2000): Is anybody there? Critical realism, chronic illness and the disability debate. *Sociology of Health and Illness* 22 No1, 797-820.

Williamson,C (Eds) (1992): *Whose Standards?: Consumer and Professional Standards in Healthcare*. 1st ed. Vol. 1. Routledge, London, 246.

Wils,J (1998): The establishment of a large collaborative trial programme in the adjuvant treatment of colon cancer. *British Journal of Cancer* 77 (Supplement 2), 23-28.

Wilson,RG; Hart,A; Dawes,PJ (1988): Mastectomy or conservation: the patient's choice. *BMJ* 297, 1167-1169.

Yates,PM; Beadle,G; Clavarino,A; Najman,JM; Thomson,D; Williams,G (1993): Patients with terminal cancer who use alternative therapies: their beliefs and practices. *Sociology of Health and Illness* 15 No.2, 199-216.

Yellen,SB; Cella,DF (1995): Someone to live for:social wellbeing, parenthood status, and decision making in oncology. *J.Clin.Oncol* 13 No5, 1255-1264.

Young,JC; Garro,LY (1982): Variation in the choice of treatment in two Mexican communities. *Soc.Sci.Med.* 16, 1453-1465.

Zaniboni,A (1997): Adjuvant chemotherapy in colorectal cancer with high-dose leucovorin and fluorouracil: impact on disease-free survival and overall survival. *J.Clin.Oncol* 15 No.6, 2432-2441.